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Ethnicity, learning disability, and the Mental Capacity Act 2005: a social constructionist ethnography of an integrated learning disability service

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PhD Thesis

Faculty of Health and Social Care

The Open University

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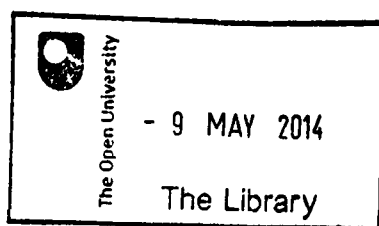
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ABSTRACT

This thesis explores how the Mental Capacity Act 2005 (MCA) is operationalised within an integrated statutory learning disability service and examines how the legislation is manifested in everyday lived experience of an ethnic minority. In England and Wales, the MCA established a framework for assessing cognitive decision-making ability with mental capacity conceptualised as 'objective', 'rational' and person-specific. Taking as points of departure rationality and individualism which are associated with Western liberal democracy, the MCA evokes interest in how the notion of mental capacity is understood within different cultures. In the statutory context, with on-going heated debates about the epistemology of mental capacity, there is the need to examine how professionals concretise an arguably nebulous concept in their roles. These aforementioned issues are addressed in this thesis through examination of data collected during two phases of ethnographic fieldwork in a London local authority. Proposing a new relational model as a theoretical approach, it is argued that ethnicity, learning disability, and mental capacity emanate from human interactions; therefore, greater attention should be paid to context and localised meanings to better understand how they interact in everyday living.



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CHAPTER ONE. SETTING THE SCENE FOR MY THESIS

Situated within the sociology literature, this thesis interrogates the social categories ethnicity, learning disability, and mental capacity. The thesis is framed within social constructionist epistemologies. As such it addresses the situated understandings that professionals formed and utilised in their statutory duties towards learning disability service users. The thesis also attends to institutional practices that generated and sustained the enactment of these three social categories in fieldwork. The Mental Capacity Act 2005 (MCA) in particular covers a wide range of issues which until it was originally proposed were believed to be governed by common law. Spanning private and public spheres of life, some of the matters included: whether family members could make decisions on behalf of each other, who could advocate for people considered to lack mental capacity to make their own decisions, if doctors could treat people in their best interest where they lacked capacity, and when researchers could include people unable to consent to their participation.

The MCA affirms the right of people to make decisions for themselves but it also extends the duty to assess mental capacity to non-professionals. The empowerment of (non)professionals to assess capacity together with the increased role of the State in private affairs highlights the need for increased research on the applications of the MCA in practice. In particular, research is needed on areas such as: whether the MCA is operationalised holistically or discretely in statutory contexts, and the framework by which different professionals make decisions about which MCA powers or duties apply. The MCA also suggests that cognitive conditions such as learning disability, dementia, and brain injury are more likely to trigger mental

capacity assessments; therefore there is the need to address how this latter supposition manifests in the life of service users.

My interest in research into applied aspects of mental capacity, ethnicity, and learning disability emanate from my professional and life experiences. As a Black British man of Ghanaian ancestry living in the United Kingdom, I confront the implications of my ethnicity daily. My lived experiences in London bring the social inequality arising from ethnic (or racial) classification to the fore of my consciousness and this partly influenced my choice of profession as a social worker. Whilst practising as a social worker it was my witnessing directly the propensity of the State to incarcerate young black men and/or people classified as learning disabled that motivated me to enrol on a Master of Research (MRes) degree to seek some intellectual answers. In the course of my Master's I was inspired by my tutor to investigate the MCA's attempt to resolve the delicate balance between care/control of learning disability service users (Keywood, 2006). Thus I explored the generic impact of the MCA on learning disability social work in my Master's dissertation. My PhD research has built on my previous understandings. But I have also been galvanised from my discussions with advocacy groups, fellow researchers, and stakeholders to think differently from currently accepted conceptualisations of mental capacity as cognitive and individualistic. Thus as well as data gathered from months of ethnographic fieldwork, my life history, and experiential social work knowledge, I have drawn on sociological literature to compile this thesis. In the main I have been influenced by social constructionism in my conceptual thinking, a departure on the applied literature on mental capacity which draws predominantly on the disciplines of medicine, law, and philosophy.

Keeping to theme of scene setting, in the remainder of this chapter, I explain the MCA in greater depth. Furthermore I explain the epistemological and theoretical underpinnings of my thesis. Then in Chapter Two I discuss the literature on the concepts of ethnicity, learning disability, and mental capacity. The literature review chapter has been compiled from searching the Social Care Institute for Excellence (SCIE) database of MCA-related multidisciplinary studies¹, specialist databases, and within journals in psychiatry, jurisprudence, and social work. I have also benefitted from discussions with professionals and widely published researchers in my substantive concerns (McManus et al, 1998). In Chapter Three I explain my rationale for affiliating with the qualitative research paradigm as well as justify why ethnography is the most appropriate methodology for my thesis. Subsequently in Chapter Five, I account for my fieldwork practices. The MCA's statutory duty to assess capacity has led to the creation of new Research Governance Framework (RGF); however, few empirical studies have been conducted within the MCA's RGF so, I address this issue in Chapter Five. In Chapters Six, Seven, and Eight I present my analyses of empirical data. Lastly, I reflect on how my subjectivity shaped the research in Chapter Nine. As a final note, I also deliberate on the epistemological and methodological possibilities of relational sociology to advance future research in my area. Now however, as a prelude to these forthcoming sections I continue with scene-setting by explaining the main provisions of the MCA.

Substantive provisions of the MCA

¹ <<http://www.scie.org.uk/publications/mca/index.asp>> (accessed on 28 July 2013 and regularly throughout my PhD).

In Chapter Two, I discuss the MCA's history in detail but as part of scene-setting, in this section, I briefly explain the reasons why a new law on consent was deemed necessary. The MCA was enacted because of recognised ambiguities and loopholes in health and social care practice around informed consent, particularly from the late 1970s onwards. Responding to these debates, in 1989, the head of the judiciary in England and Wales (formerly known as the Lord Chancellor) began consultations to bridge these legal anomalies. Overlapping the Law Commission's work on mental capacity was the increasing topicality of adult protection, which was driven by deinstitutionalisation and the 'rights agenda' (Law Commission, 1995). Encouraged to move from large hospitals into the community, learning disability and mental health service users demonstrated previously unrecognised capacities to adapt to everyday living. Simultaneously, community care exposed them to new social demands and professional networks from which they had been denied the skills and knowledge to cope with, thereby heightening legal uncertainties in their care – for example, the question of who had the power to make decisions on their behalf in emergencies. Thus the MCA was designed to enshrine the principle that people have the right to make decisions for themselves but it also provides more robust legal and ethical frameworks for decision-making for those with impaired mental capacity.

The primary legislation is augmented by a Code of Practice (Department for Constitutional Affairs (DCA); 2007) which explains in more practical terms how the Act should be operationalised in day-to-day practice:

Everyone working with and/or caring for an adult who may lack capacity to make specific decisions must comply with this Act when making decisions or acting for that person, when the person lacks the capacity to

make a particular decision for themselves. *The same rules apply whether the decisions are life-changing events or everyday matters.* (DCA; 2007; p15; emphasis added).

The MCA is based on the functional model of assessing capacity which postulates that mental capacity should only be assessed where doubts arise about a person's mental capacity in respect of a specific issue at a particular time. The MCA is also based on the 'unwise' decision principle, therefore notionally, mental capacity assessments cannot be proposed just because of concerns about the likely consequences of a person's choices. The functional model is a two-stage process of capacity assessment. Firstly, assessors have to determine whether a person has 'an impairment of the mind or brain' or there is 'some sort of disturbance affecting the way their mind or brain works' (DCA, 2007; p41). If there is an impairment of the mind or brain, then there is a second stipulation that the condition should be impacting on the person's ability to make a decision at a particular time. In the MCA, the latter requirement is termed the decision and time-specific principles because it stipulates that mental capacity assessments should be about a particular decision; mental capacity should also be assessed at a discrete period of time and that one assessment should not influence the outcome of another. The MCA Code of Practice advises that professionals who assess capacity should keep formal records, however in day-to-day care arrangements capacity assessments need not be documented. Furthermore where a person has been assessed as lacking mental capacity, the MCA stipulates that any action done of their behalf should be in their 'best interest' or what 'the 'best course of action' is for the person.' (Joyce, 2007; p7).

Advocates consider the MCA as empowering because it introduces new rights and duties in respect of incapacitated people. The MCA allows for advanced directives (AD) by which people can stipulate their wishes for a future in which they may lack capacity. Through ADs, people can outline medical treatments that they should not be subject to at a later date. In addition, the MCA empowers people to nominate others as Lasting Power of Attorney to prospectively make decisions about their property, welfare, and medical treatment. Stanley and Manthorpe (2008) also argue that the 'time-specific' principle should be seen as beneficial to service users because it requires practitioners to assess capacity frequently, and at a time that the person is most capable. For example, if professionals know that immediately after medication a service user's decision-making capacity is inhibited, then they are obliged under the MCA to assess their capacity at a different time when they are unaffected by prescription drugs. Another right introduced by the MCA for service-users is that in such assessments, all necessary communication aids have to be provided. Upon 'reasonable steps' being taken to establish (in)capacity people can make decisions on behalf of others if in their best interest and furthermore, where these decisions are to do with 'care and treatment' there is immunity from prosecution (Brown and Barber, 2008).

Aside from new formal rights, the MCA links into the broader Safeguarding Adults policy framework (ADSS, 2005; DOH, 2000) by seeking that 'adults who lack capacity to make decisions for themselves are protected from abuse.' (DCA, 2007; p243). Firstly, the MCA posits that people lacking mental capacity are susceptible to abuse and, as a result, it introduces a new crime of wilful neglect and abuse towards incapacitated people. Equally importantly, the MCA re-establishes the Court of Protection (COP) to be the final arbiter on capacity and 'best interest' disputes.

Therefore where statutory services and families dispute care plans, COP judges adjudicate on the way forward. Additionally COP appoints officers called Deputies to represent and look after the affairs of people who lack capacity and do not have family or friends.

COP's role in the resolution of contentious mental capacity assessments has thrown into sharp focus the care/control role of the State. Increasingly COP is being drawn into ruling on cases previously regarded as outside the remit of the State. For instance in 2010 COP judges pronounced on whether a woman of Bangladeshi origin classified as learning disabled could be involved in an arranged marriage (Beckford, 2012), an issue previously regarded as cultural practices outside the remit of statutory services (Clawson and Vallance, 2010; Dunn et al, 2008; Ryan, 2012).

In general, learning disability service users and people considered to have 'cognitive problems' (MCA Code of Practice, DCA, 2007; p34) have been central to debates about whether the MCA is useful. Historically in the UK people informally identified as socially incompetent have also been regarded as lacking mental capacity to manage all their affairs and in need of 'care' (Hirst and Michael, 2010). As a result opponents of the functional model of mental capacity warned about the possible role of social stigma in assessments. As long ago as 1993, Carson argued that because certain social categories were associated with incapacity, the first stage of the functional model would create a 'diagnostic threshold' thereby increasing the propensity for labelling some people as incompetent. Echoing Carson's arguments, more recent critiques have highlighted that the functional model lacks redress against the ingrained societal prejudice of certain people becoming intrinsic to capacity assessments (Keywood, 2006). More broadly, other writers oppose the concept of mental capacity. Winnick (1995) for instance has raised the possibility that an

assessment of incapacity may become a mark of social disadvantage and impact on a person's sense of self-worth.

In a more expansive sense, Carson and Keywood's work show that social categories are contested to some degree. For instance although learning disability is the statutory classification for people who are seen to display maladaptive behaviours or have less than average intelligence (DOH, 2001; Northfield, 2004), it is contested by advocacy groups. Those who oppose the category learning disability do so because it suggests that disability is inherent within the individual rather than caused by societal barriers, as implied by the social model (Stevens, 2008). As such user groups prefer the term 'learning difficulties', a position that I align with. However, I use learning disability in this thesis to reflect statutory parlance. Similarly some people contest official ethnic classifications because notwithstanding that conceptually ethnicity applies to everyone; officially, it has become associated with ethnic minorities and black people. This explains why the nomenclature Black and Minority Ethnicities (BME) is prevalent in statutory social services (Mason, 2000). However the association of BME with black people leads others who consider themselves 'white' or 'Asian' to resist the category (Cole, 1993).

Thus there is an arguable dissonance between how social categories are operated by statutory services and how individuals experience or articulate these concepts in lived experiences. Nevertheless alongside categorisation of people into groups of service users, statutory agencies also classify need. As a case in point, England's statutory guidance Fair Access to Care Services (DOH, 2003; 2010) stipulates four bands of eligibility, which are low, moderate, high, and critical needs. Therefore with social services provision, categorisation of need and people are interdependent in the sense that some services are only reserved for persons assessed

as displaying statutorily determined personal characteristics. Consequently accessing statutory services exposes people to official categorisations simultaneously as social categories are contested. To these on-going scholarly debates, this thesis adds some originality by showing how three social categories intersect in the sphere of service delivery. I accomplish this task by applying social constructionism as an epistemological framework for understanding how and why social categories are created.

Epistemological frames: applying social constructionism to research on social categories

Social constructionist influenced research starts from the premise that individuals actively create meanings in their everyday lives through their immersion in social networks. From this vantage point social constructionists expose the interactions that lead to meaning-making (Gubrium and Holstein, 2008). Applied to my research concerns social constructionism draws attention to the situated-meanings of ethnicity, learning disability, and mental capacity. This latter point entails moving away from any supposition that ethnicity, learning disability, and mental capacity are innate human qualities universally displayed independent of culture and local contexts (Mallon, 2007). However, my argument is not that in other societies people do not consider that their peers cannot make decisions for themselves or that people exhibit (dis)similarities. Rather as Hacking explained ‘[s]ocial constructionists about *X* tend to hold that: ‘*X* need not have existed, or need not have been at all as it is. *X*, or *X* as it is at present, is not determined by the nature of things; it is not inevitable.’ (1999, p6; original emphasis). Thus if *X* is taken to represent the substantive concerns of my

research then Hacking's theorisation would hold that they have to be understood as historically contingent exemplars of modernity within Western intellectual and socio-political contexts. Social constructionist research involving the categories ethnicity, learning disability, and mental capacity, would therefore explore the developments of these concepts in order to explain why and how they have taken on their current meanings (Parton, 2009).

To explain how people come to embody social categories, social constructionists draw attention to the process of classification as a starting point (Keogh, 2005). Here conceptual parameters of phenomena are mapped out through micro, meso, and macro interactions. As Hacking (2006) has shown elsewhere, classification may include medicalisation or geneticisation, whereby attempts are made to prove that categories are an intrinsic part of humans instead of arising from their social situations. With respect to ethnicity for instance, some long-standing research traditions still aim to show that ethnic groups have genetic lineages even in the face of contra evidence that intra-group differences matter as much as inter-group disparities (Carter and Dyson, 2011). However, notwithstanding countervailing knowledge, classifications can become bureaucratised 'as an objective way to determine who needs help, but the relation is reciprocal. The criteria used by the system in turn define what it is to fall under various categories' (Hacking, 2006; unpaginated).

To paraphrase Hacking, once social categories become institutionalised, people at the micro level define themselves in relation or opposition to statutory classifications. Arguably bureaucratisation also entails identification because social classifications become assigned to people on the basis of their apparent correspondence to taxonomies. At the group level individual classification attains the

feature of categories, whereby ‘outsiders’ such as professionals are imbued with power to group together those who are *prima facie* similar (Jenkins, 2000). The model elucidated here is, however, not sequential: classification, identification and categorisation can occur synchronically through complex social and institutional arrangements (Hacking, 1999).

In a contribution to social constructionists’ theorisation of categories, Zerubavel (1996) posited that classifications are not ‘out there’ in the world and differences (or similarities) are neither as sharp nor close as we take them to be. In Zerubavel’s model, humans are brought up to ‘lump’ things of resemblance together, thereby ignoring acute differences. Simultaneously, we ‘split’ things of the same characteristics and exaggerate their apparent anomalies. Taking learning disability as an example, in everyday life, professionals come across people who display abilities that confound the agreed conceptual parameters of the label, yet services operate as if everyone labelled learning disabled is similar notwithstanding their marked differences. An alternative example is that people of white and black parentage are described as black (for instance Barack Obama); in this way, they are ‘lumped’ together with black people and equally ‘split’ from white people even though they could be described as either. Zerubavel postulated that ‘lumping and splitting’ is a process of socialisation, which enables us develop shared-meanings to make sense of a complex world. Zerubavel’s work also implies that in our social relations we are continuously (re)creating conceptual boundaries of phenomena.

The theoretical discussion up to this point suggests that social constructionist ideas can be usefully applied in research interested in interrogating the concepts of ethnicity, learning disability, and mental capacity. At one level, the concepts of classification and categorisation arguably support a view that the substantive concerns

of my research are ‘constructed’ because individuals (re)formulated these concepts. Given that at the micro level people continuously (re)create meaning of concepts and classifications, social constructionism enjoins researchers to attend to context and actions: ‘the meaning of these [i.e. ethnicity, learning disability, and mental capacity] and everything else is contingent on the actions of people, who must supply classifications, interpretations, and narratives to make sense of them.’ (Harris, 2008; p233). While a convincing epistemological explanation of social categorisations, social constructionism has been at the forefront of the ‘science wars’ in which scholars debate the nature of reality (Hacking, 1999). As Elder-Vass (2012) shows, some theorisations of social constructionism take relativist positions akin to postmodernism to deny foundational knowledge. An avowedly relativist position is problematic for reasons which I now outline below.

The meaning of ‘reality’ in my thesis

Within the realm of statutory services professionals’ duties and powers are set out in legislation. For instance Section 7(1) of the Local Authority Social Service Act 1970 says ‘Local authorities [or social workers] shall, in the exercise of their social services functions, including the exercise of any discretion conferred by any relevant enactment, act under the general guidance of the Secretary of State.’² This later citation supports the view that any professional employed in statutory services operates within a context where their responsibilities and duties are set out: they are required to assess mental capacity, or meet the needs of learning disabled service users, or that professionals have to assign ethnicity and other social categories. Even if professionals can exercise some discretion when discharging their responsibilities,

² The National Archives <<http://www.legislation.gov.uk/ukpga/1970/42>> (accessed 20 March 2011).

their duties exist inasmuch as they are stipulated by laws, which professionals and citizens alike are mandated to follow.

A social constructionist who has theorised about reality is Searle (1996). Searle proposed that the concepts of ontological objectivity and institutional facts can explain different conceptualisations of ‘reality’. To Searle there are certain aspects of the world that cannot be denied. We cannot argue against the existence of mountains, for example, or that people use money in everyday transactions: thus mountains and money are ‘ontologically objective because their mode of existence is independent of any perceiver [e.g. professional] or any mental state’ (Searle, 1996; p8). Similarly we may conceive of statutory assessments of mental capacity or learning disability or the census because they occur independently of an individual’s interpretation. Those events that occur as a result of governments discharging their functions can be termed “‘institutional facts”, [...] so called because they require human institutions for their existence.’ (Searle, 1996; p2). For professionals operating within statutory services, ethnicity, learning disability, and mental capacity are therefore institutional facts. Given the ‘reality’ of the statutory contexts in which social services operate, my research attends to ‘epistemic subjectivity’ (Searle, 1996) by exploring the agency (or discretion) that professionals and service users display within the bounded reality of responsibilities, duties, and entitlements provided by law. Going by Searle’s exposition of ontological objectivity, my thesis arguably avoids the heated debates about the (in)compatibility of social constructionism with realism (Elder-Vass, 2012). Through application of Searle’s work my thesis sidesteps debates about the nature of ‘reality’ which in any case can lead to infinitely regressing arguments about foundational knowledge (Delanty, 1997).

Social constructionists argue that institutional facts do not exist in themselves but are called into being through the use of language (Weinberg, 2008; p25). Consequently social constructionism suggests that rather than existing outside of social contexts, ethnicity, learning disability, and mental capacity may rather be 'language games'. Deriving from the work of Wittgenstein 'language games' refers to how the repeated use of a word or phrase leads us to believe that it has essential characteristics independent of ourselves (Rasalingham, 2009; p325 - 326). According to Weinberg (2008) 'language games' is a useful analytic tool in constructionist research because it highlights that 'truths' are only validated within the contexts of their application. Thus in social constructionist theorisations, one way by which 'reality' is created is through the development of common understandings and shared meanings. Recalling Zerubavel's notion of 'lumping and splitting' already described above, while in their routine practices professionals may not agree on the finer details of the concepts of ethnicity, learning disability, and mental capacity, they nevertheless develop working understandings. Consequently, how these concepts are operationalised will vary from service to service, hence another reason why constructionist-inspired research attends to context.

The philosophical exploration of social constructionism in this section shows that it offers rich epistemological possibilities for my research. Epistemologically, social constructionism draws attention to how social interaction necessitates creation of individual classifications. People then become identified with such classifications resulting in social categories when similar people are put together as a group. Social categories are 'real' because once embodied, they shape how people visualise their identities and on the other side, how institutions mobilise and respond to individuals.

Using this broad epistemological framework, I have also adopted Foucault's work on discourse and governmentality to theorise how social categories are actually formed.

Theorising social categories

In this section, I explain Foucault's theories on discourse and governmentality to show how they influenced my understanding of ethnicity, learning disability, and mental capacity within statutory contexts. Foucault's work postulated how and why social categories become embodied, therefore it has direct relevance for my research. Drawing attention to institutional processes, Foucault also explained why people sometimes accept instead of reject categories. In the second half of this section I also explain an alternative theory on social categories proposed by Van Gennep and Victor Turner.

Foucault: discourse, power/knowledge, and governmentality

In Foucauldian thought '[w]hat is constructed ("made") then, are "subjects", and Foucault means here that when human beings are "made subjects," they are also *subjected*, that is, constructed as objects of power' (Miller, 2008; p252; original emphasis). To Foucault, power is evidenced in many forms, one of which is discourse. Mills (2004, p15) suggests that in Foucauldian thought discourse 'is something which produces something else (an utterance, concept, an effect) rather than something which exists in and of itself and which can be analysed in isolation.' In this sense, discourse encompasses the institutions, practices, and systems, which shape our perception of reality by stipulating to us how we should conceive of the world around us. Additionally discourses exist in multiple forms (including speech)

but institutions set rules of recognition and acceptance. As such in Foucault's conceptualisation, discourses are simultaneously inclusive and exclusive. At the same time as determining the kinds of knowledge accepted as truth discourses provide grounds for disregarding other evidence. For this latter reason, even though there is a multiplicity of discourses through the exercise of power, certain knowledge is privileged over others.

Situating the present deliberations on Foucault's ideas within my research concerns, the concept of discourse potentially explains why medical model explanations of learning disability or mental capacity dominate the operationalisation of statutory services. This exposition of discourse is also helpful because it places the categories of ethnic minority (or BME), learning disability, and mental capacity within an institutional context – for example the social services bureaucracy – where certain understandings are privileged with concomitant procedures specified about how professionals should intervene. Placed within statutory contexts, the Foucauldian concept of discourse highlights practices such as referrals, assessments, and care package reviews, which result in formal classifications of service users and thresholds of need.

Moving from individual reality to knowledge about groups of people – i.e. social categories – Foucault introduced the concept of bio-power. In one sense bio-power is the process through which governments collate, document, and categorise the minutiae of subjective characteristics. There is, however, a feedback loop with bio-power because on the aggregation of subjective characteristics, individuals adopt such knowledge to regulate themselves. Thus once an individual accepts that an IQ of 70 or less is in fact learning disability, they adopt this knowledge and accordingly act along the lines stipulated for those so classified. Bio-power may be summed up as:

One or more truth discourses about the ‘vital’ character of living human beings, and an array of authorities considered competent to speak that truth [...] Modes of subjectification, through which individuals are brought to work on themselves, under certain forms of authority, in relation truth discourses, by means of practices of the self, in the name of their own life or health, that of their family or some other collectivity, or indeed in the name of the life or health of the population as a whole (Rabinow and Rose, 2006; p197).

As such, bio-power critiques realist ontology that social categories exist outside their creating discursive powers (Yates, 2005). Drawing on Foucault, ethnicity, learning disability, and mental capacity may be seen as embodied categories, which are ascribed to people through bio-power. Firstly, ‘truths’ about the inherent characteristics of learning disabled people, or ethnic minorities, or mentally incapable people are privileged through discursive power. Then at the population level, social categories (or groups) of such people are identified through the exercise of bio-power. The goal of bio-power however is control of populations (Mills, 2010): even if the intention is to help, there is a rationale to control or manage populations in order to efficiently organise assistance. Therefore the notions of discourse and bio-power give rise to questions about how much agency individuals exercise in their daily life because Foucault could be read as theorising that ‘realities’ about people are created by external power without their involvement (Miller, 2008).

Some writers have re-interpreted Foucault to argue that his theorisation of power allows for agency. Turning away from expositions of power as necessarily

oppressive, Foucault saw it as diffused, exchangeable, and requiring a body (material entity) to be exercised. Additionally Foucault conceptualised power as inherently countervailing of itself (Tremain, 2005; p4). Researchers drawing on these Foucauldian ideas about how people challenge dominant discourses about their lives focus at the micro level of lived experiences. It is suggested that in their everyday lives, people exercise agency by challenging externally imposed categories about themselves. Barron (2002) has shown through empirical research that some women classified as learning disabled resist the label as oppressive. Similarly, Goodley ((2003); (Goodley and Rapley, 2002)) has suggested that self-advocacy may be one means by which people resist being labelled learning disabled. In ethnicity research, inspired by Foucault, researchers have explained how in their everyday lives, ethnic minorities operate culture as fluid, thereby interrogating any essentialist assumptions about cultural identity (Kalra, 2006; Nayak, 2005). In this body of work social categories are accepted as 'real' albeit imposed in people's lives, and researchers explore at the micro and meso levels how people challenge classifications.

In other work inspired by Foucault, researchers show that people exercise agency by actively co-opting discourses about their social categories. In some of the learning disability literature for instance, it has been shown that some groups mobilise around a shared and claimed sense of disability for political action (Dowse, 2001). Furthermore in Foucauldian thought, individuals bearing these categories co-opt and accept them because there may be associated benefits. Conceptualised this way, the economic and social benefits (such as services, closeness to power, citizenship recognition) attached to service users accepting categorisations outweigh the drawbacks. Consequently, service-users (and their families) on occasion exercise power to seek (self)categories .

On a macro level Foucault coined the concept of governmentality to link bio-power to the actual practice of governing: ‘the deliberations, strategies, tactics and devices employed by authorities for making up and acting upon a population and its constituents to ensure good and avert ill’ (Rose, 1996; p328). Similar to Foucault’s conceptualisation of power, theorists on governmentality propose that Foucault conceived of government as diffused through social and professional networks, so that in Foucauldian thought, the State is dispersed (Rose et al, 2006). Researchers drawn to Foucault’s social constructionist stance on social categorisation therefore tend to analyse statutory and non-governmental organisations through which State power is exercised ‘at a distance’ (Rose, 1996). This draws attention to statutory services as potential sites of governmentality as the former is imbued with powers and duties to categorise people to meet their needs.

Foucault’s work is usually applied in poststructuralist work but here, I have drawn on the work of Miller (2008) to explain how Foucauldian ideas relate to my research. While helpful, Foucault may be interpreted as proposing an ontological theory in which people by necessity are categorised. Paradoxically therefore, while Foucault’s work is praised for debunking claims of objectivity, arguably it could be criticised for proposing a singular ontological state for humans. An alternative theory on social categorisation which holds that people are sometimes in-between categories is liminality which I have also drawn upon in my research

Van Gennep and Victor Turner: liminality as an alternative state of being

In their various writings on social ontology, Van Gennep and Victor Turner proposed the concept of liminality as useful in explaining the nature of being. Liminality describes the state of in-betweeness (Thomassen, 2009); as such the concept is

analytically useful in researching statutory services which exist to serve particular social categories and thresholds of need. With regards to integrated learning disability services, in order to be eligible for services, a person needs to conform to the category of learning disability and additionally, their needs have to be determined as within the eligibility criteria. Statutory services operate, therefore, as if people can be identified neatly as either learning disabled/not learning disabled or that professionals can incontrovertibly determine when needs shift on the eligibility criteria. However, on occasions some objects, events, or even concepts do not fit into their pre-determined categories, calling into question the efficacy of classification systems. Van Gennep (1960) and Turner (1966; 1969) deployed 'liminality' to explain the transition period between classifications at which point things are unclassifiable and/or miscategorised.

Van Gennep was the first to propose the ontological theory of liminality in 'The Rites of Passage' (1960). In his theorisation of liminality, Van Gennep begins thus: '[t]he life of an individual in any society is a series of transitions from one age to another and from one occupation to another [...] progression from one group to the next is accompanied by special acts' (1960; p2-3). In Van Gennep's postulations, changeovers are always accompanied by 'rites of passage', which are ceremonies held to mark the occasion of change. Taking the life of a person classified as lacking mental capacity as a case in point, by Van Gennep's conceptualisation, such an individual is born into a group – e.g. people are born into families, or an ethnic group, or socio-economic class – and then later, the person becomes (re)categorised as an adult, and subsequently as incapacitated. At the point of being classified incapacitated, the 'rites of passage' would be the assessment (taking into account the functional model), during which other professionals and materials (e.g. forms, pens) will be assembled to declare that the person lacks capacity. Van Gennep further sub-

categorised rites of passage into three stages; namely, separation, transition, and rites of incorporation, with the second stage (transition) identified as the liminal period. According to Van Gennep these sub-categories do not manifest simultaneously in all rites of passage and one stage might be more important in some cases. But within statutory services, people classified as disabled arguably experience all three sub-categories: they become separated from children's services and are incorporated into a new system (adult services) at 18 years. In statutory services, the point at which children move to adult services (the liminal period) is also called 'transition' (DOH, 2006; p14) as in Van Gennep's work.

Whereas Van Gennep's theorisation focused on periods of transition, Turner explored the characteristics of people undergoing change, thereby making the concept of liminality even more relevant to discussions about social categorisations. Turner conceptualised periods of separation and incorporation in rites of passage as fixed and liminality as fluid:

The attributes of liminality or of liminal personae ("threshold people") are necessarily ambiguous, since this condition and these persons elude or slip through the network of classifications that normally locate states and positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial. (Turner, 1969; p95)

Building on Turner's ideas cited above, it may be said that 'threshold people' defy convention because they do not fit neatly into established social categories:

‘[t]heir condition is one of ambiguity and paradox, a confusion of all the customary categories’ (1966; p97).

Van Genneep and Turner’s work can be criticised for viewing European societies as superior, hence the charge of racism can be applied to their work. Furthermore, their work could be interpreted as suggesting that events occur linearly, as in for instance Van Genneep’s sub-categorisation of the rites of passage I have described above. Notwithstanding these criticisms, Van Genneep and Turner’s ideas offer fruitful avenues for theorising about statutory services. The concept of liminality suggests there are certain service users who would not conform readily to categorisations. As a result of not fitting pre-allocated classifications, such people may provoke anxieties in professionals leading to their isolation from social networks. For empirical research based within statutory services, one line of enquiry that the concept of liminality provokes is professionals’ action on encountering people transitioning between categories.

Conclusion

In this introductory chapter I have explored social constructionist epistemologies and used two ontological theories on social categories to set the scene for my thesis. I have proposed that social constructionism augmented by Foucault’s concepts of discourse, power/knowledge, and governmentality offers useful ways by which researchers come to know or explain social categories. Researchers can gain knowledge about social categories by studying what people do in their everyday lives including discharging their duties within institutions. As they go about their routine activities and encounter complex worlds, according to Zerubavel (1996) and Jenkins (2000), people compartmentalise certain phenomena, and in time, people create

similarities and differences between objects (or concepts). Because we live within societies characterised by institutions which exercise power, people can assign individuals to social classifications; the latter translates into social categories if people are put together into groups. Foucault's ideas that I have examined above suggest also that agency is exercised because categories developed through institutions may become the yardsticks by which people self-identify. More succinctly, there is a feedback loop between lived experiences at the micro level and macro institutional discourses. In one sense however, while social constructionism may be said to be outlining how researchers can identify social categories, social constructionists are arguably proposing a theory of ontology on social categories. The latter point flows from the constructionist supposition that by our very natures, we engage in 'lumping and splitting' of concepts (Zerubavel, 1996). It is for this reason that Van Gennep and Turner's work also holds promise for my research for they too propose the alternative ontological theory that people are not necessarily always categorised because they periodically exist in states of in-betweenness. Having discussed the theoretical influences of my research, in the forthcoming chapter, I review the literature on ethnicity, learning disability, and mental capacity, to show how I have derived my research questions.

CHAPTER TWO. LITERATURE REVIEW

This chapter reviews the literature on ethnicity, learning disability, and mental capacity, which are central concepts to my research. Taking into account the viewpoint of the research participants, my thesis explores how these three social categories are operationalised within an integrated learning disability service. A key dimension of my thesis is the institutional context of statutory services taking as a starting point what professionals do within their employment setting. Theoretically, my research is influenced by social constructionism and as such, I take as a point of departure that learning disability, ethnicity, and mental capacity are ideas or ‘constructions’ (Hacking, 1999) which nevertheless impact on lived experiences (Carter and Fenton, 2010). The general approach in this chapter is therefore to chart how the three social categories are understood and researched, paying attention to how social categories become embodied categories in everyday living.

Ethnicity, learning disability, and mental capacity: analysing threads

One commonality between the categories of ethnicity, learning disability, and mental capacity is that they are relatively new concepts. Historically in the UK, people judged to have maladaptive behaviours or below-average intelligence have been described pejoratively (Wright, 2000). The Mental Deficiency Act 1913 marked the first attempt at classification based on the new pseudo-science of eugenics and the development of tools to ‘measure’ intelligence (Race, 2002). However the term ‘learning disability’ was first used by Samuel Kirk at the beginning of the 1960s in the United States of America (USA) (Scanlon, 2005) and it is now the accepted

statutory term in the United Kingdom (UK) (DOH, 2001; 2009). Even taking into account the classification systems enshrined in the 1913 legislation learning disability and mental capacity have been informally seen as indicating peoples' cognitive capacities.

However in liberal democracies (e.g. the UK) the capacity to make decisions assumed socio-political, legal, and ethical importance. O'Shea (2011), writing about the history of consent, noted that one characteristic of modernity in Europe was that governments derived their legitimacy from the consent of the population instead of from God. According to O'Shea the English civil war caused a break with the notion of divine right of sovereigns to rule without their population's consent, a revolution given further impetus by the American Declaration of Independence in 1776 which stated that "Governments are instituted among Men, deriving their just powers from the consent of the governed." (cited in O'Shea, 2011; p12). Thus liberal democracy arose from the idea that people could choose those who ruled them at free and fair elections during which individuals considered information, weighed up their options, and arrived at rational decisions about who should govern them. Therefore implicit in the conduct of democratic elections is the supposition that voters have mental capacity thereby leaving aside '[the] question: how and to what extent can a section of the citizenry, identified by impairments in their intellectual functioning, participate in a defining activity of a democratic society, namely voting in a general election?' (Redley, 2008; p375).

The assumption that citizens in liberal democracy have mental capacity additionally underpinned the notion of informed consent which also required that doctors sought patients' explicit agreement before medical treatment (Buchanan, 2004). Specifically, within the UK, from the 1980s onwards it became clear through a

serious of judicial decisions that legal ambiguities existed around informed consent. In respect of medical treatment, it was noticed that informed consent was underpinned by common law instead of codified legislation (Grubb, 1998). As such doctors could be charged with battery in certain situations if they treated patients without their consent (Wilson, 1996). During the case of *Re F* (1990), at the same time as authorising the forced sterilisation of a woman presumed to lack capacity to consent, the House of Lords also recognised that however beneficial, no one had the legal right to make decisions on behalf of another person.

With growing pressure for clarification of the legal framework in England and Wales, the Law Commission began consulting in 1989 on a new law on informed consent; however, it was only in 2005 that MCA was enacted. The MCA's long gestation highlights how complex the issue was regarded at the time, as well as the on-going demographic changes likely within the nearly 20-year period of consultation. In the time that it took to enact the MCA, mental capacity came to the fore in other Western countries. Demographic changes (ageing population and altered family structures), increasing stress on human rights, medical advances, and reconfiguration of learning disability services from institutional to community delivery led to the growing prominence of mental capacity (Carney, 1997; Glass, 1997; Hale, 1997). Consequently the concepts of mental capacity and learning disability may be seen as historically contingent within liberal democracies – for example, the UK, USA, Canada, and Australia – which are also regarded as Western or populated mostly by white people. This raises questions about how the concepts are understood or operationalised by people of different cultures or how being seen as ethnically different influences (self)categorisation (Biswas and Bhaumik, 2003; Mir et al, 2001; O'Hara, 2003).

Because the MCA is law, it can be said to have formally constructed the social classification ‘mental capacity’ (Jenkins, 2000), which historically has been informally associated with the classification ‘learning disability’. My research is motivated by the need to understand the role of statutory services – a site of power - in the lives of those categorised as mentally incapable (or learning disabled) who are ethnically different. Through statutory services, UK governments have imbued professionals with powers, duties, and technologies to categorise service users with the view to meeting their needs. One such category is ethnicity, which I now expand upon in Part One.

Part One. Ethnicity

People (self)categorised as ethnically different from the dominant white population were involved in my fieldwork; consequently, the concept of ethnicity is important to my analyses. Framed around the question ‘what is ethnicity?’, in this section, I explore the relevance of the sociology literature on ethnicity for my research.

The multiple dimensions of ethnicity

In sociology, it is now accepted that ethnicity is a socio-political construction emanating from human interactions (Alexander, 2006). Drawing on social constructionism Moore (2003a) identified three ethnicity models, namely: primordialism, modernism, and mobilisationism. Primordialist models consider ethnicity a consequence of long-standing historical and ‘archetypal traits’ amongst a group of people. Moore argues that this model is outdated because it implies that ethnicity is static whereas in his view, most researchers now consider ethnicity formation a dynamic and fluid process. As a result, the modernist model is preferred

because it captures the 'dialogical and relational' nature of ethnicity (Moore, 2003a; p93). Here, because of prevailing social tensions, ethnicity is created as a means of including 'us' and excluding 'them'. Extending this line of thinking, in the mobilisationist model, ethnicity is another tool in the prevailing group conflict over resources. Sometimes this approach is referred to as the instrumental model (Fenton, 2003; p98).

Moore's exposition of ethnicity is characteristic of the sociology literature which although orientated towards social constructionism nevertheless emphasises the 'reality' of the situations leading to ethnicity's creation. Thus, it is assumed that there are real, tangible, and visible markers such as how people dress, their religious practices, skin colour, and customs which coalesce into ethnicity. In the quest for power, actors mobilise the symbolic markers to create 'them' and 'us'. As a further clarification Jenkins (2008) distinguished between 'groups' and 'categories'. In the former individuals believe that they share similarities (be it physical appearance, history, ancestry, culture) whereas in the latter, people are characterised as identical by 'outsiders'. One way by which the State categorises is through census whereby people select from prior classifications. In the UK official ethnic categorisation includes Black and Minority Ethnic (BME), or ethnic minority (Aspinall, 2002; Cole, 1993; Mason 2000).

There are conceptual difficulties however with nomenclature. Taking 'ethnic minority' as a case in point, Mason (2000) notes that it is generally applied to people without white skin tone; in this sense, it is now replacing 'race', which is discredited for assuming that skin colour reflects genetic differences between people. Besides, where people are offered the opportunity to describe their ethnic identity in their own words, they employ divergent terminology from official categories. Aspinall (2012)

conducted a survey of 326 young people in which they were asked to describe their ethnicity using their own terms instead of selecting from prior classifications. According to Aspinall only 14 respondents referred to their skin colour preferring instead to highlight their mixed heritages. Interestingly most of the options on census forms are based on skin tone so from Aspinall's survey it may be concluded that self-identities do not always match official categories.

Mirroring the structure/agency debate, the issue of individual/group identity is also important to conceptual explorations of ethnicity. If ethnic identity exists, then by corollary, there is the need to address the structural (group) or agency (individual) contexts of its formation. Jenkins (2008) argues that groups and categories are always implicated in each other's formation: identifying your similarities through social interaction necessarily requires labelling the Other. As the interactional, spatial, and conceptual differentiation of the Other is on-going, group boundaries are always fractious and in-being. An alternative view from Jenkins' is that ethnicity need not emanate from groups. According to some writers, ethnic groups do not exist in and of themselves; instead, it is what people do and the choices they make that produce outcomes identified as ethnic relations:

[T]he mobilisation of ethnic identities is relational [...]: we do not therefore belong to groups, we (occasionally, often, sometimes, never) relate to significant others, in specific social contexts, by drawing on available identities including ones which could plausibly be called "ethnic". Crucially some particular *cultural attribute or performance* takes on special significance in creating and sustaining the social

boundaries between people. (Carter and Fenton, 2010; p5; emphasis added).

Echoing the above, Brubaker takes issue with the notion of ‘groups.’ In his view, groups are socially constructed: their boundaries and (di)similarities between members are enacted. By ‘*invoking* groups, they [powerful actors] seek to *evoke* them, summon them, call them into being. Their categories are *for doing*—designed to stir, summon, justify, mobilize, kindle and energize.’ (Brubaker, 2002; p166; original emphasis). Brubaker, therefore, challenges any assumptions that there are collectivities which form ‘naturally’ to be identified as ethnic groups. Brubaker may also be taken as arguing against any supposition that, empirically, it is possible to determine such entities called ‘groups’. Thus groups are socially or conceptually constructed. The discussion to date suggests heated conceptual debates about the nature of ethnicity, which are also paralleled by contentions about how ethnicity can be operationalised in field research.

Operationalising ethnicity

In the UK, contravening Brubaker’s postulation of ‘ethnicity without groups’ the category of BME collectivises ethnic minorities and has consequently become synonymous with ethnicity (Mason, 2000). What Brubaker calls group-thinking therefore underlines researchers’ operationalisation of ethnicity: research in ethnicity is arguably underpinned by an assumption that there are social groups who form the basis of collective ethnicity identities. Ethnicity may be conceived in temporal or spatial terms (Malesevic, 2011). In temporal terms people identify their ethnicity by recourse to historical lineage whereas in spatial terms, ethnicity is assigned to people

on the basis that they inhabit a smaller geographical and statistical space within a bigger white political entity. Thus, despite convincing evidence that ethnic minorities have lived in the UK for centuries (Dabydeen et al, 2010), their historical lineage in the UK is constructed as emanating from post-war immigration, and in spatial terms, they are simultaneously considered a smaller unit of a bigger white population. Conceived of as a group, people become reified into the category of BME which is conceptually predetermined (as in the census).

Influenced by group-thinking, empirical studies have operationalised ethnicity or BME either through the researcher assigning ethnicity to the participants or accepting ethnicity that has been self-defined (Ellison, 2010). These, however, give rise to other complications. To start with, where researchers assign the participants' ethnicity, they replicate some of the conceptual difficulties I have discussed above because ethnicity can refer to skin colour, place (or country) of origin, geographical space, religion and culture. Without asking participants, researchers risk erroneously assigning ethnicity on the basis of visible markers such as skin tone, name or religious/and cultural practices. Studies adopting researcher-assigned ethnicity are therefore in danger of conceptual conflation and to mitigate this, participant self-identification is advised (Bradby, 2003). However not every participant may be able (or want) to self-identify – for instance not every person communicates “conventionally”. If self-identification is the methodological approach then people assessed as lacking mental capacity for instance may not be regarded as capable of understanding their culture, historical lineage, or the totality of their ethnic identity.

Furthermore people may change their ethnic self-identification over time depending on circumstances and timing. As an illustration of the latter point, a person identifying as Black British of Ghanaian origin may decide to self-classify as solely

Ghanaian if in Ghana. Arguably, in effect, any attempt to research ethnicity through self-identification risks conceptual reification. The charge of reification is particularly difficult to escape in ethnicity research where people are at the sharp end of socio-economic inequality. Motivated by a desire to effect political change researchers may need to present marginalised people as a group, and communities may need to form political alliances on the basis of static categories (Banton, 2005). Therefore, in applied research, participant self-identification could lead to reification and we may perceive a disjuncture between current substantive understandings of ethnicity as a fluid concept, and praxis requirements for a static ethnic category.

Arguably, however, the issues of reification and conflation can be addressed if ethnicity is seen not as inherent within groups or individuals but as emanating out of social relations. A relational approach draws our attention to the conclusion that, essentially, ethnic categories are lived in day-to-day interactions (Stanfield, 2011).

In my research I have conceived of ethnicity as emanating from social relations. Adopting Brubaker's model of ethnicity without groups (Brubaker, 2002), in my conceptualisation, a person's ethnicity is not derived from their incorporation within a group of people similar to themselves because the group dissolves to be replaced by an individual acting out their ethnicity in given contexts: '[o]ne might just as well speak here of *negotiations* or *conversations*; the underlying idea would remain the same regarding the primacy of contextuality and process in sociological analysis.' (Emirbayer, 1997; p290; original emphasis). Flowing from Emirbayer's idea is the implication that we are all ethnic minorities depending on context: a white person could be a minority in Britain if they found themselves in a room of ethnically-different people and vice versa. More importantly, in such a context, the white

person's ethnicity does not dominate; rather different ethnic relations beyond the white/black or majority/minority dyads emerge.

Contravening the on-going epistemological debates I have outlined above, there seems broad agreement in the sociology literature that culture is analytically central to discussions about ethnicity (Gunaratnam, 2003; Mac an Ghaill, 1999; Nagel, 1994). In my research I employ culture as another analytic thread between ethnicity, learning disability, and mental capacity. This is because the concept of culture leads to allied questions about how people of different ethnicities conceptualise learning disability, how people in different cultures relate towards individuals so classified (Jenkins, 1993; 1998), and how culture impacts on decision-making (Bekker et al, 1999; Garro, 1998).

Exposing culture

Culture is considered a difficult concept to define because it is now employed in all disciplines. A helpful starting point, however, is Wuthnow et al (1984; p3): '[culture is] the symbolic-expressive aspect of human behaviour. This definition is sufficiently broad to take account of the verbal utterances, gestures, ceremonial behaviour, ideologies, religions, and philosophical systems generally associated with the term culture'. Some writers suggest that we are living the 'cultural turn' (Murji and Solomos, 2005) by which it is meant that having previously been the predominant concern of anthropology (Faubion, 2001), culture, with its attention to meaning-making is now analytically central to all social science research (Alexander, 1996).

In his analysis of the conceptual relevance of culture to ethnicity, Malešević' (2011) argued that 'ethnicity can never be reduced to culture, neither can it be explained without extensive reference to culture [...] Although ethnicity is not culture there is no ethnicity without culture' (p77). Malešević's exposition is helpful because

he located culture within the political, suggesting that individuals call on their cultural markers within spaces of socio-economic and structural change. In this sense culture is a social construction. Groups can create markers to delineate themselves during structural changes or powerful actors can make claims on behalf of a group from the State, which in turn can accede or resist these requests (Nagel, 1994).

In a contribution to the discussion Dewalt et al (1998) proposed that culture has explicit and tacit elements. The explicit parts of culture are visible, for instance: costume styles, food consumed, social norms, and artefacts. In contrast '[t]acit aspects of culture largely remain outside our awareness or consciousness' (p260). Dewalt et al's point is that culture consciously and/or unconsciously drives actions and that aspects of culture include what people routinely do in their lives. The concept of tacit culture further suggests that in decision-making people may draw on an internalised way of doing things within their social networks, which may be based on kinship or more formal professional ties. Relatedly the notion of culture also implies shared values which guide actions at the micro, meso, and macro level. Thus culture encompasses what people do in their everyday lives, including patterns of behaviour within organisations which lead to taken-for-granted knowledge and localised re-interpretation of social customs (Kunda, 2002; Taylor, 2004). As Soysal noted '[c]ulture has become the *commonsense* in ordering, organising and managing the world (2009, p5; original emphasis).

Summary

Placing the literature review within sociology, I have shown that conceptually, ethnicity emanates from social relations. There is a consensus that the concept of ethnicity exists inasmuch as it is debated as an idea and people are (self)categorised as such. Within the UK 'ethnic minority' or 'BME' applies to people different from the

dominant (usually white) population. These aforementioned concepts are also contested: firstly, because they treat people of different cultures as a group, and secondly, because they are considered a euphemism for 'race.' I have also shown that there are convincing arguments for researchers in ethnicity to focus on the individual rather than groups as the unit of analysis in ethnicity research (Caughey, 2006) because such an approach recognises individual agency to affect their identity. Having discussed ethnicity in Part One, I now explore how the concept of learning disability has been operationalised in statutory services and how this impacts on lived experience.

Part Two. Learning disability

My aim in Part Two is to situate my thesis within the multiple research and policy agendas in learning disability. Firstly I explain how learning disability became formalised as a statutory imperative. Then, influenced by Graham (2010, p141) who argues that 'the everyday lives of people defined as having learning disability have been adjusted for the realisation of governmental values', I show how top-down classifications influence lived experience. By necessity this means that I have to chart some policy (r)evolutions within learning disability statutory services to identify the context of my research. From the institutional standpoint, I discuss integrated services, the site of power (Rose, 1996) for categorising and managing the lives of people classified as learning disabled. Then I discuss supported living and risk which, being policy strands in adult social care, also impact on the lived experiences of service users.

Learning disability: a historical overview

Since the post-war period in the UK learning disability has been operationalised through statutory services, making the point of service delivery important to research. The key legislation is the 1970 Local Authority Social Services Act which led to the formation of local authorities' Social Services Departments (SSDs), and the professional title 'social worker' (Buchanan, 2011). Contemporaneously there was increasing stress on deinstitutionalisation and equal rights of learning disability service users and SSDs were charged with moving people classified as learning disabled from long-stay institutions into the community (Atkinson et al, 1997). In the 1990s Conservative governments implemented the 1990 National Health Service and Community Care Act (NHSCCA). The thrust of the NHSCCA was an ideological need to introduce 'market forces' into adult social care and SSDs were re-organised under the policy of care management (Lewis, et al, 1997). While previously SSDs had a duty to assess need and provide services, from the 1990s onwards, they were required to split their functions between assessments and commissioning of services. Where needs were identified by SSDs they would 'purchase' learning disability services within a mixed economy of provision from voluntary, statutory, and private organisations (Cambridge et al, 2005). The publication of Valuing People (DOH, 2001; p14) signalled new policies of promoting service users' independence and choice but community care and marketization were maintained (DOH, 2001; 2009).

The historical overview of the policy and concepts of learning disability here is aimed at showing the continuities of the past with the present and their influences on research agendas. Bearing in mind that learning disability is a social category, one strand of current research agenda involves interrogating the label 'learning disability' either from medical model or social science perspectives. My thesis takes a social

science perspective and is anchored in the tradition of exploring society-person interactions.

Agendas in learning disability research

In this section, I expand further on research agendas in learning disability with the following issues in mind:

- How and why researchers seek to understand the lives of people classified as learning disabled.
- In the post-war period policy has aimed at integration of health and social services (Wistow, 2012), therefore I address the rationale and methodologies for studying integrated services.
- Substantive and methodological agendas in researching how current policy imperatives around adult learning disability services are achieved.

Researching the lived category of learning disability

Substantive aims in researching learning disability from social science perspectives have changed alongside consensus on effective methodologies. This is not to say that these changes occurred sequentially but rather, at ‘moments’ in time, researchers become occupied with some substantive concerns which they believe can be answered with particular methodologies (Denzin and Lincoln, 2003). In the immediate post-war period researchers sought to understand how deinstitutionalised people lived in the community. Edgerton (1984; 1993) and Atkinson (1985) are recognised as methodological innovators in deinstitutionalisation because unusually for research on learning disability at the time, they adopted qualitative (ethnographic) methods taking a longitudinal approach (Jenkins, 1993). Following these original works, there emerged another substantive agenda in learning disability research aimed at

interrogating the category 'learning disability.' Arguably this new research direction arose through a convergence of theory and politics. Theoretically, postmodernism, poststructuralism, and social constructionism which all aimed to challenge foundational knowledge and the possibility of unitary identity attained credence. Simultaneously, the social model of disability was gaining prominence. Although aimed at situating disability as a societal rather than an individual phenomenon and thereby politicising the debates (Oliver, 1992; 1996; 1998), the social model nevertheless inspired researchers to question the category 'learning disability'.

For instance Siminski (2003) employed quantitative methodology to show that 'disability is socially derived' (p711) by analysing data from the Australian Bureau of Statistics' 1998 Survey of Disability Ageing and Carers. Goodley (2001) conducted an ethnography of a self-advocacy group which was inspired by the social model and poststructuralism. From this study, Goodley argued that 'Impairment [including learning disability] is social not the product of isolated individual pathologies.' (p221). Similarly drawing on 'feminist poststructuralism' and using a life story approach, Roets (2009) argued that through self-advocacy, people labelled learning disabled were active agents in constantly challenging 'the dominant master narrative about them' (p697).

In one sense my research departs from the traditions discussed up to now because I pay relatively more attention to the statutory and institutional contexts leading to learning disability classifications. In another sense however, my research keeps to the substantive agenda in the social science literature on learning disability around: the need to interrogate the category and the need to understand how people so classified live. Moreover my research explores how current policies on learning disability, which aim to enhance service users' 'rights', 'independent living', 'control

[over their lives]' and 'inclusion' (DOH, 2009; p. 29) are actualised in service users' lives (Fyson and Kitson, 2007; Graham, 2010). A key policy in this regard is independent living which includes supported housing. In the next section I explore the literature on supported housing, which was the site for my fieldwork with a service user.

Understanding supported housing

After gaining credence in the 1990s, supported housing became a central plank of policy for service users to attain increased choices, independence, and social inclusion (Kinsella, 2009).

Supported housing is typically accommodation where an individual has a tenancy agreement with the landlord of the property. Care and support is provided to an individual in their home either by the landlord or by another organisation(s) or through a completely personalised 'bespoke' arrangement. (DOH and Housing Options, 2010; p6)

The key criterion for supported housing is that service users sign a tenancy agreement (Fyson et al, 2007). Therefore mental capacity is important to the present discussion because service users have to understand the implications of their choice of accommodation and tenancy.

Although important to current policy in learning disability, the dearth of empirical studies on the daily life of service users in supported housing is also recognised (Bond and Hurst, 2010; Simmons and Watson, 1999). The few studies have shown that the term 'supported housing' can refer to many types of tenancies sometimes indistinguishable from residential living. For instance McConkey and Collins (2010) found in their study that that 30 people lived in the same

accommodation; however, because they all had individual tenancies, they were classified as supported tenants and not institutional residents. In terms of methodology, a review of the international literature on supported housing by Kozma et al (2009), which built on earlier work by the same authors (Beadle-Brown et al, 2007) is worth further discussion because it includes relatively recent studies and a large number of papers were re-analysed. Kozma et al (2009, p195) found that most papers utilised quantitative methodology: 'In most studies (66 of 68) investigators took a quantitative approach, using a variety of instruments. People with intellectual disabilities had virtually no input into the design of studies.' While helpful in evidencing trends quantitative methods nevertheless do not fully capture the detail and minutiae of everyday lives of service users (Shaw and Gould, 2001).

The literature reviewed here suggests the need for critical research exploring the lived experiences of supported tenants. Researchers need to observe the everyday lives of tenants to understand how the policy aims of 'independence', 'choice' and 'inclusion' are actualised. While researchers have studied how choice is operationalised in learning disability, these were within residential homes (Antaki et al, 2009; Dunn et al, 2008; 2010), hence the need for research sited in supported living where the policy framework is explicitly geared towards enabling service users' 'independence'. The literature reviewed here also highlights the need for qualitative approaches: methodologically, as 'choice' and 'independence' are value-laden concepts, qualitative rather than quantitative methods may be required (Moriarty, 2011). Having so far discussed learning disability from the lived-experience perspective, I now want to shift focus to another substantive concern – i.e. the point of service delivery - since the second site of my fieldwork was an integrated learning disability service.

Researching the integration of learning disability services

Learning disability is a social category operationalised by statutory services through integrated services. Integration of the National Health Service (NHS) and local authority social services has been a longstanding policy aim since the post-war period (Wistow, 2012). It is assumed that integration increases choice of services by changing the spaces within which social care is delivered: 'This co-location of services will make easier the joint assessment of patients' needs.' (DOH, 2000; p71).

Services' integration has occurred along a continuum: in 'full' integration statutory services combine their physical and organisational spaces, and budgets. On the other hand 'relative autonomy' refers to informal coordination between services (NHS Confederation, 2010). Furthermore, different terminology is applied to professional practice within integrated services including:

- **Interdisciplinary working:** where there is full integration and distinct professionals with their own identities work in a coordinated manner towards an apparent single goal.
- **Inter-professional working:** distinct professionals work in separate teams but with formalised processes for sharing information and working.
- **Multi-professional team:** a group of professionals working together but maintaining distinct professional identities (Nancarrow et al, 2012; p12 -16).

In the integration literature the models of professional practice within integrated teams identified by Nancarrow et al are used inter-changeably, making it difficult to identify the organisational context of studies. Furthermore, even though integration has been a long-standing policy aim, there is little agreement on what constitutes an

integrated service. Also, there are on-going debates about the efficacy of joint-working. I address these issues in more detail below.

Substantive agendas in integration research

Perhaps due to frequent organisational changes in adult social care (Duffy et al, 2010), most of the literature focused on structural integration and its impact on outcomes for service users (Ham and Oldham, 2009; Syson and Bond, 2010; Humphries and Curry, 2011). A strand of the literature on structural integration addressed economic costs and benefits; sometimes concluding that financial savings can accrue (Turning Point, 2010). The literature on outcomes for service users also recorded ambiguous findings. From their evaluation of two integrated services, Davey et al (2005) noted that integration led to increased communication between professionals; however, this did not sufficiently impact on outcomes for the older people involved in the study. The lack of consensus on the benefits of structural integration led Cameron et al (2012) to conclude after a systematic review that ‘the evidence base [for the benefits of integration] is patchy and more research is required to sharpen and broaden our understanding of these outcomes’ (p18).

Where ostensibly focused on the impact of integration on front line practice, studies rarely mentioned the reality of daily social care practice. Instead they focused on possible conflicts between different professions. Maslin-Prothero and Bennion (2010) noted confusion between social workers and medical staff about their roles and responsibilities, leading to conflict between managers. The British Association of Social Workers (BASW) reported concerns among members about dominance of health professionals and ethos in management of integrated teams (Godden, 2012). Sometimes concerned with the erosion of social work values within integrated teams, researchers took a defensive posture to argue for the (potentially) unique contribution

of social work (Herod and Lymbery, 2002). Few studies focused on how professionals within integrated services cooperate. Additionally, the rare studies taking joint-working from the point of view of social workers tended to be based within older people's services (Emilsson, 2013) or in adult mental health (Bailey and Liyanage, 2012; Liyanage, 2012). However, notwithstanding the many policy changes in service delivery, learning disability remains the responsibility of social services (DOH, 2001; 2009; Stevens, 2004), which are increasingly provided through integrated teams (Appleton, 2009). Therefore, there is the need for studies sited within integrated learning disability teams.

There is sparse literature on empirical studies which were situated within integrated learning disability services, and/or focused on exploring what professionals conceive their duties to be towards service users, with the MCA as context. Arguably in order for this knowledge gap to be addressed, there is a need for research methodology such as ethnography that will enable researchers to observe the minutiae of practice and service users' everyday lives over a period of time (Shaw and Gould, 2001). My research addresses these gaps in the integration literature.

Within the broader context of this chapter, the literature reviewed to date shows that in the post-war period, statutory services have been important institutional contexts for categorising people as learning disabled and meeting their assessed needs. Additionally some social science literature seeks to interrogate the category of learning disability by understanding people's lived experiences, or their social situation (for example, housing, employment prospects, and leisure activities). In policy terms it is now agreed that those categorised as learning disabled have equal rights to choice and independence (Lawson et al, 2008) and the MCA is conceivably part of the same human rights agenda in social services (Joint Committee on Human

Rights (JCHR), 2008). In the upcoming section, I argue that any research on learning disability within a statutory setting also has to pay attention to risk because the latter is now a pre-occupation of statutory services (Titterton, 2005).

Operationalising risk in social services

It is now recognised that ‘risk might be regarded as being everywhere [in statutory services], but perhaps nowhere properly understood.’ (Warner and Sharland, 2010; p1035). By this latter point research in adult social care has to address understandings and operationalisation of risk in statutory services. Therefore, my research investigates perceptions of risk within my fieldwork sites. In this section, I explore three theoretical approaches to risk namely realism, cultural/symbolic, and governmentality perspectives (Lupton, undated)³, and how they have influenced my research. The cultural/symbolic and governmentality perspectives are broadly social constructionist and have enabled me to understand and explain my fieldwork data, critique practice, and form alternative explanations to operationalisation of risk within my research sites. This is because in the main, social constructionist theorisations of risk attend to how wider socio-cultural practices and localised meanings shape individual (or collective) interpretations of risk (Lupton, 1999). On the other hand, the realist literature suggests that risks exist in service users’ lives (Webb, 2006); as such, I have utilised this theoretical approach to foreshadow actors’ motivations for action within my research sites.

³ From webpage <http://www.academia.edu/757961/1_Sociology_and_risk> (accessed 24 April 2013).

Realism, risk, and policy responses in social care

From the viewpoint of statutory services, Kemshall et al (1997) proposed that a realist understanding of risk underscores service provision. Diminishing funding for statutory services has resulted in more stringent eligibility criteria, which in turn have culminated in two developments. Firstly, professionals have to concentrate resources on the neediest; the flipside of this is the requirement to assess those who would be at most risk without services. Secondly, organisations have responded to less funding by developing better systems for resource allocation, and concomitantly better risk assessment tools. These two issues led Kemshall to conclude elsewhere that: '[t]he identification of risk and the categorisation of risks into thresholds for intervention and service delivery have become key mechanisms in the rationing of scarce social care resources.' (Kemshall, 2002; p82). Kemshall's theorisation, therefore, ties risk with needs assessments. In policy terms, people classified as learning disabled are viewed as 'vulnerable' because they are deemed more likely to face risk (JCHR, 2008), or be mentally incapable (Brown, 2011) thereby triggering the need for State protection (MCA Code of Practice, 2007).

A by-product of the realist supposition that service users face risk in their lives is that a strand of the literature attempts to quantify the probability of some service users being victims or propagators of risk. Some studies suggest people classified as learning disabled are more likely to commit arson or sex offences (Barron and Baner, 2004; Lambrick and Glaser, 2004). By contrast other writers argue that learning disability service users are susceptible to abuse (Calcrafft, 2007) depending on the following: managers' decision-making, the knowledge and aptitude of care staff, the behaviour of service users (whether with 'challenging' behaviours or not), and the design of the built environment (White et al, 2007). Of the abuse that learning

disability service users are more likely to suffer, sexual abuse has been highlighted (Mitchell and Glendinning, 2007), although this stance is challenged for implying that learning disability service users are inherently vulnerable (Hollomotz, 2009).

Based on these realist assumptions, in statutory services actuarial tools have been developed to help professionals predict risk to certain service users (Royal College of Psychiatrists, 2008). Implicit here is that professionals, being more capable of processing risk-associated information, are better risk assessors than lay people (Stalker, 2003). As such professionals are imbued with duties and powers to assess and manage risk. The distinction between power and duty is important because with the former, practitioners can exercise discretion in their situational responses whereas with the latter 'local authorities [social workers] have no choice to do something as it is imposed by law. No allowance for shortfall of resources is acceptable, although professional discretion may inform the manner in which the duty is informed [discharged]' (Gaylard, 2011; p20). In the next section, I explain professionals' duties where abuse is suspected in adult services.

Policy responses to risk and vulnerability in adult services

In policy terms where risk is deemed 'real', the term abuse is used to denote its operationalisation:

[A]buse' covers a wide range of actions. In some cases, abuse is clearly deliberate and intentionally unkind. But sometimes abuse can happen because somebody does not know how to act correctly – or they haven't got appropriate help and support. It is important to prevent abuse, wherever possible. If somebody is abused, it is important to investigate the abuse and take steps to stop it happening. (DCA, 2007; p244)

In the quote above, based on the assumption that abuse exists, professionals are enjoined to ‘prevent’ abuse or investigate where reported. Policy responds further by categorising abuse into the following: financial, physical, sexual, psychological, neglect and ‘acts of omission’ (MCA Code of Practice, 2007; p245). Furthermore, statutory guidance, No Secrets (DOH, 2000), mandates agencies to establish joint procedures for responding to ‘alerts’ that an adult is at risk or has been abused. However, although concerned with wider strategic and organisational issues, No Secrets does not prescribe procedures for investigating reports of abuse (Fitzgerald, 2008).

Faced with the absence of a codified statutory framework in safeguarding vulnerable adults (Law Commission, 2008), statutory agencies draw on a mixture of piecemeal legislation and inter-agency procedures (Naylor, 2010). One such inter-agency procedure is the ‘London multi-agency policy and procedures to safeguard adults from abuse’ (SCIE, 2011; p51-102), which outlines a seven-stage sequential model cited below:

1. ‘Alert’ – This is the reporting stage of abuse. ‘Alert’ may be from the public, other agencies and/or professionals.
2. Referral and decision – Formal notification through documentation, and at this stage, the notified organisation decides its response.
3. ‘Strategy discussion or meeting’ – Inter-agency discussions between professionals to plan a response to an ‘alert.’ If it is decided that further investigation is required, a lead investigator will be assigned. Alternatively it may be decided that the alert is more a criminal matter,

in which case it is referred to the police or that no further action is warranted.

4. Assessment and investigation – Further details sought about the nature of risk posed/faced.
5. Case conference and protection plan –Winding down of investigation at a multi-agency meeting; plan formed about how to protect the victim – the Protection Plan.
6. Monitor and review – Inter-agency meetings to discuss the progress of the Protection Plan.
7. Closure of the Safeguarding Adult process.

Spanning through this sequential model is risk assessment: ‘Risk assessment is integral to the whole process of safeguarding and is specifically concerned with the identification of specific risks to a person covered by the Safeguarding Adults policy and procedures.’ (SCIE, 2011; p50). Furthermore, the SCIE procedures show that each stage of the model depicted above has allotted timescales for their completion, and although roles are assigned for all statutory agencies, social workers are usually the lead professionals in safeguarding work. The discussion up to date suggests, therefore, that any research situated in social services would need to take risk perceptions as one of the contexts of the study because professionals have a duty to assess and manage risks.

Problematizing the realist literature on risk

Some drawbacks in the realist literature are identified in terms of conceptualisation, methodology, and substantive concerns. Some researchers take issue with how the realist literature conceptualises risk within statutory services. For instance there is

lack of service user involvement (Wallcraft and Sweeney, 2011; Duffy and Gillespie, 2009) especially learning disabled people; and there is little knowledge of how professionals' and users' ethnicity impact on risk assessments (Mitchell and Glendinning, 2007). With regards to quantification of risk susceptibility of learning disabled service users to crime, there are heated methodological debates. Some writers argue that prevalence rate of crime committed or suffered by learning disability service users depends on *inter alia* whether people accessing services are included, whether an IQ measure of intellectual disability is applied, and how 'offence' is categorised (Simpson and Hogg, 2001; Lindsay, 2002). Thus there is a complicated picture around how to determine whether learning disability service users are at risk of perpetrating or being victims of crime. Research on the use of risk prediction tools also highlights the need to attend to professional discretion. As a further elucidation of this latter point, Kemshall (2010) reports that professionals rarely use the actuarial tools for risk prediction in the ways intended because they prefer narrative case analyses instead of formal calculations. Equally, other studies show that professionals sometimes circumvent actuarial tools on moral grounds (Broadhurst et al, 2010), or on the basis that risk assessment procedures are substantively and systematically ineffective (Fish et al, 2009; Munro, 2005; Munro and Hubbard, 2011). Holland et al (2002) therefore enjoin researchers to focus primarily on the social processes that lead to risk (categorisations) instead of debating what crimes are suffered or committed by learning disability service users. My research responds to the call by Holland et al. I have focused on the organisational processes by which service users become identified as 'criminals' or 'vulnerable' using social constructionist perspectives on risk which I outline in the following section.

Social constructionist perspectives on risk

In my research, I have utilised social constructionist perspectives which include cultural/symbolic and governmentality approaches as conceptual tools to explore fieldwork data. Following a distinction by Lupton (1999), social constructionist perspectives on risk can be placed along a continuum with 'weak' and 'strong' versions on either end of the scale. In the 'weak' version it is argued that risk exists but is only identified or actualised within wider macro structures. Considered within the setting of statutory services, the weak version would hold that what is categorised as risk is the outcome of professional and service user interaction mediated by institutional contexts. 'Strong' versions of social constructionism postulate that everything we take for granted in the world emanate from social relations (language, meaning, and institutional contexts) rather than exist independently of our perceptions (Kitzinger, 2000). Thus the 'strong' social constructionist theorisation of risk takes a more relativist stance on the meaning of risk than 'weak' social constructionism (Lupton, 1999; p30).

'Strong' social constructionism: governmentality and risk

According to Taylor-Gooby and Zinn (2006, p408) 'governmentality approaches posit risks as entirely constructed, the product of social processes which enforce particular power relations'. Brought to theorisations of risk, governmentality perspectives take two analytic standpoints. Firstly, there is attention to broader socio-political concerns with controlling the population (Rose, 1999; Rose et al, 2006). Secondly, attention is paid to the micro-location of professionals (or experts) within a nexus of domination. Advocates of governmentality also posit that in addition to external control, power creates conditions and knowledge for people to engage in self-regulation: power is 'already 'out there' in the patterning of social practices and discourses, acting

through, and able to steer, the capacities of individuals to act *as if for themselves*' (Tew, 2006; p35; original emphasis). The governmentality thesis on risk therefore seeks to uncover the means (or technologies) by which issues or people become categorised as risk(y), and the feedback loops through which such knowledge is adopted by individuals to self-control (O'Malley, 2009).

One strand of the governmentality thesis is thus concerned with interrogating how individuals' personal characteristics and history are accumulated through technology, and how this enables statutory service to engage in surveillance of those deemed 'at risk' (Yar, 2003). Influenced by governmentality, Parton (1998; 2008; 2009) has written widely about the changing nature of children's social work practice. Whereas previously social workers were mandated to intervene where children were in danger, currently professionals are charged with 'prevention' of future bad outcomes on the basis of government identified 'risk factors' to children's development. Parton's criticism lies in how these perceived risks have been actualised through technology (Parton, 1998).

The relevance of the governmentality perspective on risk for my research is that it is an alternative theoretical view to the realist underpinnings of risk conceptualisation in statutory services. Whereas the latter holds that risk inheres within the personal characteristics of service users – for example, learning disabled people as 'vulnerable' – the former posits that vulnerability is an entirely constructed concept to manage service users' needs. Influenced by governmentality, in my quest to understand lived experiences, I have taken as a starting point that externally created categories of abuse may not necessarily resonate in the day-to-day lives of service users or professionals. The governmentality literature also highlights the need for my research to pay attention to the social, spatial, and organisational contexts which lead

to individuals or events being categorised as ‘at risk.’ However, arguably, given its focus on macro-social processes, governmentality perspectives may not fully account for how externally-derived categories become embodied and actualised in people’s everyday lives. For this reason I have also been drawn on theorisations which focus on how subjective meanings translate into perceptions of risks.

‘Weak’ social constructionism and risk

One strand of the ‘weak’ social constructionist literature focuses on socio-cultural understandings of risks. This thesis is influenced by the work of Mary Douglas (1985; 1992) who wrote extensively about how given societies develop a shared understanding of risk. A key tenet of Douglas’ work was that risk is a means by which cultural groups insulate themselves from the Other - ‘[w]hat is selected in a community to be labelled as ‘risks’ are phenomena that in some way threaten moral principles’ (Lupton, undated; p13)⁴. As such, Douglas drew attention to the shared cultural understandings which led to the development and maintenance of perceptions of risk within a given society. According to Douglas, one way by which cultures police their ethical boundaries is through the adoption of taboos.

Douglas (1979) defined a taboo as ‘a ban or prohibition’ within a certain culture (p72). However what is forbidden is so taken for granted within a given society that members hardly question the reasons why. According to Douglas taboos are also a system of classification drawn upon to make sense of a complex world: behaviours or events which are collectively regarded as harmful to the moral sensibilities of the community are categorised as taboo areas and banned. But in order

⁴ From webpage <http://www.academia.edu/757961/1_Sociology_and_risk> (accessed 24 April 2013).

to hold the system of classifying taboos turns 'into automatic psychological reflexives [...] Taboos bar the way for the mind to visualize reality differently' (Douglas, 1979; p7). Douglas' theorisations of risk offer conceptual tools for my research because she may be said to take a middle ground between the governmentality and realist positions. Douglas took a realist position on risk but drew attention to cultural context: 'Note that the reality of the dangers is not at issue [...]. This argument is not about the reality of the dangers, but about how they are politicized.' (Douglas, 1996; p29). Douglas' aim was to expose how local meanings formed about a given phenomenon and the cultural practices that sustained their interpretation as risks (Lupton, 1999). Another area where Douglas' work has been useful is her postulation that what becomes identified as risk is necessarily accomplished through social processes (Elliot, 1983). In this respect, service users and their families as well as professionals actively engage in constructing or resisting risk.

Douglas' theorisation of taboos arguably highlights the psychodynamic aspect of risk conceptualisation. Thus in contrast to the suppositions of the realist literature of context-free risk assessments, emotions may lie at the heart of whether people assign or take risks (Zinn, 2006; Gillies, 2011). Anxiety about blame for 'failure' could mean that social workers operationalise a low risk threshold while, on the other side, service users may become unpredictable if fearful of constraining professional intervention (Stanford, 2012). Furthermore, with people holding different subjective interpretations of risk, there is the need to understand the rationale for action as well as professional discretion in the face of statutory procedures (Broadhurst et al, 2010; Evans, 2012).

Summary

Here in Part Two, I have reviewed the literature on learning disability to identify substantive and methodological issues for my research. I argued that learning disability is a social category underpinned by statutory classifications and operationalised within the context of integrated learning disability services. While service integration has been the hallmark of social policy since the post-war period, there has been little research on inter-professional relationships within integrated learning disability teams, and how they contribute to the discharge of statutory duties under the 2005 Mental Capacity Act. Furthermore whereas the current policy aim is 'independent living' (DOH, 2009) there is little empirical research in how having supported living accommodation as a home enhances service users' choice and inclusion. Finally, I also discussed the literature on risk given the acceptance that safeguarding is now a key policy drive in adult learning disability services (ADSS, 2005). In reviewing the literature on risks, I acknowledged that my research is influenced by realist and social constructionist perspectives. As a final note to Part Two, I want to argue that within the context of social services research on risk, my 'paradigm proliferation [is] a good thing to think with' (Lather, 2006) for two reasons. The realist position arguably defines the context that professionals work within; hence in order for me to appreciate the rationale for their actions, I need to understand that body of work. Having done so, I applied social constructionist perspectives to analyse data and critique practice. In Part Three, I discuss mental capacity, which is also relevant to my research.

Part Three. Mental capacity

In Part Three, I discuss the literature on mental capacity arguing that realism underpins current understandings of mental capacity both as a concept and an entity that can be measured. In so doing, I position my research as a critique of present theorisations of mental capacity.

Conceptualising mental capacity

An examination of the mental capacity literature should move between the general and the particular because UK literature and English law have been influenced by wider international debates. Generally there are four qualities associated with mental capacity – understanding information, appreciating information, reasoning, and evidencing a choice (Saks and Jeste, 2006) – and according to Berghmans et al (2004), this conceptualisation can be credited to the work of American scholars Roth et al (1977) and various works by Appelbaum ((1998, 2007, 2010); Appelbaum and Grisso (1995), Appelbaum et al, 1998).

There are on-going debates about the meaning and credence of each of the four qualities identified by Appelbaum – for instance whether ‘understanding’ should be prioritised over ‘appreciation’ of information (Dunn et al, 2006). Furthermore each legal jurisdiction interprets differently the four qualities Appelbaum and colleagues associated with capacity. Taking the MCA as a case in point Appelbaum and Grisso’s qualities ‘appreciate’ and ‘reason’ are substituted by ‘use’ and ‘weigh’ (Owen et al, 2009). But despite the divergent jurisdictional interpretations, there is a growing consensus amongst international scholars about the epistemological underpinnings of mental capacity (Berghmans et al, 2004). To start with, being rooted in liberal democracy, mental capacity is underpinned by the conception of an atomistic

individual who is capable of making decisions ‘rationally’. As such it is also assumed that mental capacity can be ‘objectively’ assessed. In addition, there is a legal presumption that adults have capacity, which should be task and decision-specific. These premises of mental capacity also imply that decisions with riskier consequences require more rigorous tests of capacity and vice versa. Two further areas of consensus are that capacity involves a normative judgement by an assessor in the sense that they have to judge whether the assessee has ‘good enough’ capacity.

It is also generally accepted by international scholars that laws on mental capacity should be predicated on functional models of assessment (Wong et al, 1999). In other words, mental capacity should only be assessed if doubts arose about a person’s ability to perform a specific function at a discrete time period. In England and Wales, the MCA is based on the functional model; therefore, before a person’s capacity is assessed, there should be some evidence that they may not be able to make a decision. To assess people’s mental capacity, the MCA outlines the following tests:

‘a person is unable to make a decision for himself if he is unable—

- (a) to understand the information relevant to the decision,
- (b) to retain that information,
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means).’ (MCA Section 3 (1), The TSO, 2007; p2)⁵.

In addition to the tests of capacity outlined above, the MCA is underpinned by five principles:

⁵ < http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf > (accessed on 12 June, 2013).

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action. (TSO, 2007; p19)

Arguably the most important of the above are the 'best interest' and 'unwise decision' principles. The former is seen as being a 'more objective' way of assessing a person's preferences and requires the decision-maker to use a check list to determine 'best interest' (Brown and Barber, 2008). According to Dunn et al (2007) 'best interest' is based on the assumption of individualisation because assessors have to take only the person's preferences rather than that of their family or community into account. The 'unwise decision' principle on the other hand is supposed to reaffirm the primacy of autonomy because it focuses on the process of assessing capacity instead of the outcome of a person's choices (Wong et al, 2000). Thus if after an 'objective' assessment a person's mental capacity is established, then their right to make any decision however unconventional or 'unwise' is enshrined in law.

The discussion above on mental capacity shows several strands of research with accompanying gaps in the literature. Broadly, there are on-going philosophical discussions about the nature of mental capacity and why individual autonomy should be the primary concern (Buchanan, 2004; Code, 2011). However, arguably, a drawback of the philosophy literature in general is the lack of empirical research on how people understand the yardsticks of mental capacity enshrined in the MCA. While influenced by the philosophical debates, empirical researchers have sought to develop tools to ascertain (or judge) capacity in different populations but such research can also be criticised for ignoring the role of values and emotions (Charland, 2011) in decision-making and taking it for granted that mental capacity exists..

Agendas in mental capacity research

One strand of the empirical literature seeks to develop and test instruments capacity assessment tools in different population categories. Within learning disability research where classification is dependent on IQ scores (DOH, 2001), the substantive agenda is an exploration of the links between IQ scores and (in)capacity (Arscott et al, 1999; Gudjonsson, 1992; Gudjonsson et al, 2000; Wong, 2000). Since the advent of the MCA Dye et al (2007) have ascertained the capacity of ‘mild to moderate’ learning disability service users to consent to participate in research. The research was based on the hypothesis that people would demonstrate capacity if visual aids were provided and fewer demands made on their memory. One of the findings of the study which the researchers described as ‘counter-intuitive’ was that providing visual aids and making fewer demands on the participant’s memory did not enhance their capacity to consent. The disproving of their initial hypothesis led the researchers to question the efficacy of instruments used in appraising capacity to consent and more broadly ‘suitability of current concepts of the capacity to consent being applied to all

situations in which people with intellectual disabilities need to make decisions' (2007; p173).

Nevertheless there are many instruments for evaluating mental capacity: for instance in two systematic reviews Owen et al (2006) and Okai et al (2007) respectively identified 16 and 29 different tools for assessing capacity in psychiatric contexts. Similarly Appelbaum (2007) and Lee (2010) have proposed tools for assessing capacity in medical treatment, dementia, and older people. The MacArthur Competence Assessment Tool-Treatment (MacCATT-T) is however described as 'a gold standard' (Breden and Vollman, 2004) for capacity assessments because it ascertains all four benchmarks of capacity and its reliability has been widely tested. Stemming from the proliferation of capacity-assessment tools, it is noteworthy that there are many synthesising literature reviews on capacity assessment research.

Sturman (2005) reviewed the literature on studies reporting evaluations of 12 instruments for assessing capacity and Dunn et al (2006) reviewed 23 instruments for ascertaining consent for clinical treatment and research. Although these tools are considered improvements on 'subjective' assessment, it is also recognised that they emanate from the narrow contexts of capacity to consent to research and treatment (Kapp, 2007; Moye and Marson, 2007), whereas everyday events are innumerable. As such there is a gap in the literature on how people understand and conceptualise mental capacity in their everyday lives as opposed to theorisations derived from testing people within the limited confines of hospitals or research settings. Specifically in England and Wales, this limited context is a major drawback because the MCA has expanded the areas in which capacity should be assessed thereby highlighting further the need for research on every day (non)professional understandings and operationalisation of mental capacity.

Furthermore the review of the literature on mental capacity assessment tools above shows that their use involves some normative judgement on the part of the assessor, a point recognised in English law (District Judge Ashton, 2012). Here the MCA's test of capacity can be used as a further explanation of why mental capacity assessments are not wholly objective: an assessor has to determine 'on the balance of probabilities' what constitutes 'understand' or 'use' or 'retained' (MCA Code of Practice, 2007). If capacity assessments involve subjective assessments, then by extension, the social contexts of mental capacity tests as well as power issues have to be taken into account in the discussions (Glass, 1997); however, this is rarely attended to in the empirical literature. One study which explicitly set out to address 'context' is Olumoroti et al (2007) who used one woman as a case study. The researchers described the life story of the patient as well as their medical condition in a vignette, and asked various medical practitioners to assess the woman's mental capacity. But in this research context was operationalised akin to a patient's life (or medical) history. Thus in their operationalisation of 'context' Olumoroti et al (2007) wrote about the social background of the person being used as the case study and they also described the mental illness that led to their hospitalisation. While the definitional difficulty of 'context' is recognised, usually institutional features, social processes, and the views and meanings multiple actors bring or take from a given situation are regarded as important to delineating 'context' in empirical social science (Holstein and Gubrium, 2004; Shaw, 2007). Thus, those who oppose current conceptualisations of mental capacity argue that present theories do not take adequate account of the social contexts that lead to capacity assessments.

Critiques of mental capacity

One critique of the liberal democratic legal framework of mental capacity – and therefore by extension the MCA – is Kerzner (2011). Kerzner's position is that because liberal democracy places moral value on autonomy and choice those assessed as incompetent have their freedoms constrained because they are deemed incapable of choosing. In Kerzner's view, instead of assessing mental capacity to choose, it would be more desirable for people with disabilities to have their legal capacity enshrined in legislation: 'legal capacity as [...] a social and legal status accorded independent of a person's particular capabilities [such as mental capacity]' (2011; p14). In place of mental capacity, a model of 'supported decision-making' is proposed whereby it is assumed that all people can make decisions, and that what is required is assistance to do so. Inspired by Kerzner's work, in my fieldwork, I sought to understand the care arrangements that arose within a context in which a service user's capacity was not assessed, but their carers operated on the basis that they had capacity to make decisions.

Unlike Kerzner, some writers agree with the principle of mental capacity but oppose current theorisations. Charland (2011) for instance takes issue with the exclusion of emotions from the benchmarks of capacity, noting that people draw on emotions in their decision-making. Tan et al (2006) also question the cognitive suppositions of current theories arguing that they are unable to capture the unique role of values in decision-making. Based on a mixed methodology study of patients diagnosed with Anorexia Nervosa, Tan et al found that patients passed the competency tests using MacCATT yet they did not want to eat. The researchers explain this contradiction between the participants' competence (on MaCATT) and their opposition to food through the medium of values: although competent, the

patients did not value survival and therefore did not want to eat. Tan et al's research is therefore an argument for the benchmarks of capacity to be widened beyond cognition to include human values. While Tan et al's research is an interesting contribution to the literature their arguments could be used to circumvent the unwise decision principle of the MCA. For instance professionals might force-feed people reluctant to eat on the basis that they did not have the "right" values about food. Nevertheless Tan et al are arguably the first researchers to consider the interaction between mental capacity and values. As such, their work provokes curiosity about how the MCA is operationalised within social work, a profession which explicitly espouses a value-base (Adams et al, 2002; Payne, 2005).

Finally, some critiques have started from the premise that mental capacity is a concept developed within Western (and by implication Euro-centric) legal traditions; therefore, their empirical research has sought to ascertain how the benchmarks of capacity apply in other cultures. In a review of instruments for assessing mental capacity in North American hospitals, Cattarinich et al (2001; p1476) noted 'most instruments possess two flaws: their content is not culturally informed and may not be relevant, and/or their form (i.e., structure) does not lend itself well to the assessment of Aboriginal seniors [...]'. Issues such as differences in the interpretation of body cues, and a cultural disposition among Canadian Aborigines to downplay their knowledge could not be captured by the instruments reviewed by Cattarinich et al. In the Australian literature attention is also drawn to the inefficacy of capacity- assessing instruments with Aborigines (Clements et al, 2010). LoGiudice et al (2006) reviewed some tools for assessing capacity in Australia and noted their cultural inappropriateness: whereas not all Aborigines were conversant in English, the instruments assumed that assessees were literate in English; and the conceptual

meanings of time, space, and number they took for granted were understood differently in Aboriginal culture.

Within the context of the MCA, some writers recognise that mental capacity may be understood differently by some ethnic minorities (Shah and Heginbotham, 2008; Shah et al, 2009). While for instance 'best interest' is underpinned by individualism, 'in cultures and communities where the hierarchy of the family is important, where decisions about individuals can be made by those higher up the family hierarchy the individualistic nature of the Act can clash with some cultural traditions.' (Myron and Kalathil, 2008; p26). The possibility of cultural issues impacting on capacity assessments also suggest that service users' articulation of their mental capacity may be as valid as professional opinion (Higgs, 2004). These issues have led to calls for alternative theoretical and methodological (qualitative) perspectives in mental capacity research (Berghmans et al, 2004). Furthermore, there are calls for the under-representation of ethnic minorities in capacity research to be redressed (Moye and Marson, 2007). My research responds to these recognised gaps in the literature through an in-depth study of everyday activities within an integrated service and supported living accommodation taking into account culture. It may be said that my research is unusual in mental capacity because it adopts ethnographic methodology, and it is contextualised within statutory social services.

Conclusion

In this chapter I have reviewed the literature on ethnicity, learning disability, and mental capacity, which are three central concepts to my research. Under the epistemological framework of social constructionism, I have argued that these three concepts are historically-contingent, and developed within Western socio-political

and intellectual traditions. ‘Learning disability’ replaced pejorative terms ‘idiot’ and ‘imbecile’ while ethnicity is currently preferred to ‘race’ because it is now accepted that phenotypes (including skin colour) do not necessarily reflect genetic differences (Carter and Dyson, 2011). Ethnicity is therefore now regarded as a social category (Banton, 2011). Similarly I have argued that even though there have been longstanding interdisciplinary discussions about mental capacity in the UK, the MCA established it as a social category by stipulating its existence and offering guidance on how capacity can be assessed. Overall the literature reviewed suggests the need for research into how these social categories impact on lived experience but for different reasons. There is a vast body of sociological literature which mostly addresses ethnicity qua ethnicity, hence the recent call for (re)focusing on the impact on lived experiences (Carter and Fenton, 2008). One way forward is empirical research based within statutory settings where ‘street-level bureaucrats’ allocate State resources (Lipsky, 1980). Similarly with learning disability, there is an increasing call for researchers to understand how current policy aims of independent living and choice are actualised in the everyday lives of those so classified (Graham, 2010). In terms of the MCA, it is a relatively new piece of legislation with few empirical studies conducted on its operationalisation. In paying attention to mental capacity, ethnicity, and learning disability in my research, I am also inspired by Hacking (1999) who argues that in lived experience, constructed social categories intersect.

Final note: (re)situating culture within mental capacity, and learning disability research

In the MCA Code of Practice it is theorised that culture impacts on decision-making: ‘[b]e aware of cultural, ethnic or religious factors that shape a person’s way of thinking, behaviour, or communication. For example, in some cultures it is important

to involve the community in decision-making.’ (DCA, 2007; p33). As the MCA Code of Practice is statutory guidance it stands to reason that professionals are mandated to apply its theorisation of culture in their assessment of mental capacity. However within the MCA literature, arguably no research has explored the interaction between culture and mental capacity within statutory settings (Myron and Kalathil, 2008). To address the aforementioned gap in the MCA literature, the anthropology literature may provide conceptual tools and methodological inspiration – i.e. ethnography. Anthropologists have explored how cultural practices impact on decision-making (for instance Hunt and Mattingly’s collection of papers in 1998). Culture matters to discussions about mental capacity because it provides a ‘lens’ through which actors interpret the world (McCracken, 1986), classify themselves and others, and choose between available options.

In respect of the learning disability literature, there is a strong case for (re)inserting culture into on-going substantive discussions. That ‘learning disability’ is interpreted differently within distinct cultures is agreed upon (Jenkins, 1993; 1998); however, other anthropologists argue that in certain cultures, people so classified are not necessarily regarded as lacking mental capacity (Whyte, 1998). Within the UK, it is noted that culture is rarely discussed in the learning disability literature (Hubert, 2006). Furthermore in debates about disability culture, sociologically-inclined researchers conceive of disabled people as a group who face a ‘disablist dominant [i.e. white] culture’ which the former opposes (Riddell and Watson, 2003). Thus paradoxically, while in UK statutory services culture is seen as the preserve of ethnic minorities (Jeyasingham, 2012), the disability culture literature rarely features the position of ethnic minority disabled people.

CHAPTER THREE. RESEARCHING LIVED EXPERIENCE THROUGH THE QUALITATIVE PARADIGM AND ETHNOGRAPHY

In this chapter, I situate my research within the qualitative paradigm and introduce ethnography as the overarching methodological framework. To achieve my research aims I carried out ethnographic fieldwork in two phases: the first phase was based within an integrated learning disability service, and phase two was a case study of a service user living in supported accommodation. The case study is embedded within the methodological framework of ethnography. This chapter is divided into two parts: in Part One, I discuss the qualitative research paradigm and identify ethnography and case study research within the tradition. In Part Two, I discuss ethnographic data analysis and representation with the aim of showing that researchers are enjoined to identify their subjectivity in the text. To contextualise the main discussions of this chapter on qualitative research and ethnography, I want to firstly explain my research questions.

Deriving my research questions

In this section, I revisit some of the discussions in the previous chapter to anchor my research questions in recognised gaps in the literature. Starting with ethnicity, it is generally recognised that whether self-imposed or attained through categorisation by powerful actors, ethnic classifications impact on resource allocation; however, there appears to be a disjuncture in the sociology literature. One strand of the literature addresses ethnicity *qua* ethnicity but at the expense of material and social consequences of ethnic categorisations (Carter and Fenton, 2010). On the other hand,

the applied literature struggles to avoid reification (Ellison, 2011) and as such does not reflect current substantive understandings of ethnicity as fluid. These two gaps in the literature have influenced my research interests. I want to address how ethnic categorisations impact on the decision of ‘street level bureaucrats’ (Lipsky, 1980). Within this broad area of interest, I have also empirically addressed the following two sub-questions:

- How do professionals articulate the concept of ethnicity and how does this shape their practice decisions?
- From service users’ viewpoints, what are the impacts of professional decisions-making arising from their conception of ethnicity?

In respect of learning disability, statutory services are increasingly delivered through integrated services whether these are informal arrangements between different agencies or more formal organisations which pool together budgets and locate staff in the same space. But as evidenced from my literature review there are gaps in the literature about how integrated services operate. With the MCA as a backdrop, I am interested in:

- The internal composition of an integrated learning disability service and how its structure impacts on the discharge of duties under the MCA. Who makes decisions about which duties to discharge; is the MCA implemented wholly or discretely and how are such judgements made?
- The literature review showed that risk is a prime concern of statutory services: how does this relate to the MCA? What understandings of risk are propagated by professionals and service users?
- Lastly, how are all these substantive concerns manifested in the lives of service users?

To answer these questions above I situated my research within the qualitative paradigm and adopted ethnographic methodology.

Part One. The qualitative research paradigm

Paradigmatically, both quantitative and qualitative approaches have been applied in researching social categories. However quantitative approaches are criticised because being primarily interested in the statistical correlations, they take social categories as starting points, thereby frequently leaving them (un)interrogated (McCall, 2005). As such the qualitative paradigm is preferred in researching how social categories emanate within relations and how they are operationalised in statutory contexts. Arguably qualitative research is suitable for understanding social categories because, among other aims, it seeks ‘an in-depth and interpreted understanding of the social world of research participants by learning about their social and material circumstances, their experiences, perspectives, and histories’ (Moriarty, 2011; p2).

In qualitative research ‘researchers study things [or people] in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them.’ (Denzin and Lincoln, 2003; p5). In doing so, advocates of the qualitative paradigm seek to understand phenomena from the viewpoint of the main actors, which in turn leads to at least two implications. Firstly, the need to understand subjective viewpoints makes qualitative research particularly suitable for studies which seek to explore concepts and substantive issues at the level of lived experiences. Such concepts may include the yardsticks of mental capacity

which developed principally within medico-legal deliberations and not from the viewpoint of service users (Moye and Marson, 2007; Appelbaum, 2010).

Furthermore as Becker (2009) observes, qualitative research allows for an iterative process, therefore the researcher can further refine their methodology in the course of fieldwork: '[s]uccessful researchers recognize that they begin their work knowing very little about their object of study, and use what they learn from day to day to guide their subsequent decisions about what to observe, who to interview, what to look for, what to ask about.' (Becker, 2009; unpaginated). From Becker's observation flows a second implication for qualitative researchers seeking to understand phenomena from actors' perspectives. Principles of iteration mean that qualitative research has been found useful where researchers seek to uncover the viewpoints of those who are seldom heard but nevertheless become subject to taken-for-granted understandings of their lives. Thus qualitative research is a way of challenging dominant epistemologies because researchers can orientate their study towards the concerns of participants as they garner knowledge about their social condition.

Qualitative research is now applied in nearly all substantive areas including research on 'race' issues, ethnicity (Gunaratman, 2003), disability (Barnes, 2003), social work (Shaw and Gould, 2001) and recently, in mental capacity (Dunn et al, 2010). Most writers agree that at the core of the qualitative paradigm is a quest for meaning, either from the researcher's viewpoint or that of research participants. It is also acceptable in qualitative research to collect different sources of data – for example from interviews, documents, from observations, or even videos and photographs (Bryman, 2008). However, although qualitative research is accepted in

the 'mainstream', there are on-going epistemological debates, which I now discuss to further situate my research.

Epistemological debates in qualitative research

The epistemological debates in qualitative research are varied but central to these is whether the output of research provides a window on some external truth. Initially the epistemological consensus underpinning qualitative research was positivism and realism: researchers assumed that the product of research was a window onto an independent world, hence a need for canons for verifying the quality of acquired 'truths'. In recent times, the epistemological debates have widened with strict realists on one end of the continuum and postmodernism on another. Realism assumes that it is possible to obtain 'objective' knowledge which reflects an external world or that if the right methods are followed, then stable knowledge can be acquired. However in practice realists take a more circumspect approach to 'objectivity'.

Hammersley, for instance, may be seen as a 'subtle' realist in that he acknowledges that social science can produce facts or 'real' knowledge; however, such evidence cannot form the basis of value judgements. He noted in an elucidation of his epistemological position that:

social scientists, whether realists or non-realists, have no distinctive expertise to determine what is good or bad about the situations they seek to describe and explain; or what, if anything, should be done about them. This is because even where value judgements rely on research evidence they also necessarily depend upon other factual assumptions *and upon*

value principles that are plural and often in conflict. (Hammersley, 2009; p7; original emphasis).

On the opposite side of the epistemological continuum is postmodernism, which disputes the possibility of any foundational knowledge and rules for verifying the quality of research. But as Delanty (1997; p96) has argued, postmodernism creates a problem of indeterminacy through the process of deconstruction given that its aim is 'not to reconstruct emancipatory potentials but to deconstruct the illusion of universality itself.' Taken to its logical conclusion, postmodernism leads to an infinite regress of deconstruction, and for this reason, Delanty suggests that it is on the wane as an epistemological approach. Thus, it is now recognised that in qualitative research, unchecked realism is epistemologically questionable (and perhaps unsustainable); and so is postmodernism.

It seems, therefore, that a more tenable epistemological position to underpin a qualitative research project is social constructionism. In the main social constructionism aims to combine realists' quest for foundational knowledge with postmodernists' reminder of the need for attention to power and culture that often underpin claims of fundamentality. As I have shown in the Introduction (Chapter One) my research is situated within the qualitative paradigm and is underpinned by constructionism. Constructionists take the position that knowledge creation is a social process because '[research] participants actively construct the world of everyday life and its constituent elements.' (Holstein and Gubrium, 2008; p3). Epistemologically constructionism implies that 'reality' is unstable, hence the need for researchers to garner multiple perspectives on a phenomenon. In a contribution to the discussion, Seale (1999) suggests that one methodological requirement in research which aims at

garnering multiple perspectives on a phenomenon is triangulation. The point of Seale's conceptualisation of triangulation is that the researcher gathers divergent sources of data from multiple participants: data is compared and contrasted in order to understand as full a scope of the phenomenon as possible, and not to aim for a singular view of 'reality.' Furthermore researchers understand that there can be no foreclosure to analysis as re-engagement with the data leads to new interpretations (Lather, 2010).

Qualitative research is sometimes criticised for not being generalisable, adequately rigorous, or representative of the phenomenon it purports to study. These criticisms are longstanding and originate from writers who position qualitative research as a paradigmatic opposite of quantitative research. Being repeated criticisms, questions of generalisability, validity, and sampling have been attended to by proponents of qualitative research (Morse et al, 2002; Payne and Williams, 2005; Denzin and Lincoln, 2008; Bryman, 2008). Barbour (2001, p1117) for instance has argued that the supposition that qualitative research should satisfy similar evaluative criteria as quantitative methodology 'is overly prescriptive and results in "the tail wagging the dog."' Barbour's latter cited point is that quantitative and qualitative paradigms ascribe to different epistemologies.

One further reason for Barbour's assertion is that qualitative research is premised on creativity and attention to context. It is acknowledged that qualitative researchers do not seek to generalise the outcomes of research; although if the researcher provides 'thick description' it may be possible for other people facing similar circumstances to apply their research output. It is also now recognised that the evaluative criteria for qualitative research is transparency, and researchers are

enjoined to provide as much detail about their methods as possible in order for other scholars to ascertain the credibility of their approach (Golafshani, 2003).

For my research purposes, one qualitative methodology which has been widely applied successfully in my substantive concerns of ethnicity, learning disability, mental capacity, and social care organisations is ethnography. Ethnography aims at gaining actors' perspectives through either their first-hand accounts or the researcher observing their daily lives. For instance Alexander (2006) edited a collection of ethnographic studies on 'race' and ethnicity; similarly Casper and Talley (2005) edited a special issue of the *Journal of Contemporary Ethnography* advocating the use of ethnographic methods in disability studies; while Jenkins (1998) also drew attention to the methodological utility of ethnography in researching mental capacity and culture. Similarly Pithouse (1998) and Broadhurst et al (2010) applied ethnography in the study of social work agencies. These previously cited works provided methodological inspiration and justification that I could achieve my research aims through ethnography.

Methodological utility of ethnography

Ethnographers seek to understand human actions and experiences from the point of view of the actors in their 'natural' settings: '[w]hatever the range of data collection techniques, we believe that ethnographic research remains firmly rooted in the first-hand exploration of research settings.' (Atkinson et al, 2001; p5). The distinguishing feature of ethnography from other qualitative methodologies is the simultaneous combination of key qualitative research methods. The researcher observes and participates in the activities of research participants over time, formally or informally interviews them, keeps detailed field notes, engages in reflexivity and through the ethnographic text accurately represents the group they are studying (Hammersley and

Atkinson, 2007). Furthermore, there is ‘malleability’ in ethnography (Amit-Talia, 2000; p11) because fieldwork starts with broad research questions which are refocused onto emerging pertinent issues. The methodological flexibility of ethnography makes it suitable for my thesis interests: the literature on the applied aspects of the MCA is still emerging, and there is as yet no research addressing how the three social categories of ethnicity, learning disability, and mental capacity, are manifested in practice.

Exploring epistemological agendas in ethnography

An underpinning epistemology in the quest to understand people’s lives is that everyday living is inherently complex and that this sometimes leads to a disjuncture between what people say and what they do (Scott-Jones and Watt, 2010). At one level, to reconcile the differences between actions and deeds, ethnographers are enjoined to seek a range of data sources – for example observations of people at different times, interviews of many sources, and documentary evidence – as a way of triangulating the data sources: ‘testing one source of information against another to strip away alternative explanations and prove a hypothesis.’ (Fetterman, 1998; p93). Primarily however, writers on ethnographic methodology enjoin researchers to try to understand by ‘discovering’ what people do first before attempting to interpret their actions (Schensul et al, 1999). Taken to its full implications, arguably, a predominantly inductive approach is advised in ethnographic research.

Another epistemological underpinning of ethnography which arises from the assumption of everyday living as complex and multidimensional is the need for research to be based in the setting where the activity being studied occurs. It is believed that it is only by basing the research in the context or setting in which the

phenomenon occurs that one would understand what the group actually does. As such, if a researcher is interested in how statutory agencies discharge their duties, they are enjoined to site their research where services are administered. By corollary, an attention to context (or setting) requires the need for 'thick description' by which the ethnographer describes the minutiae of the environment in which research participants were observed. In the quest to seek understanding, the thrust of the ethnography is to allow people to articulate their lived experience through their actions or their own words. The researcher, on the other hand, attempts to understand such lived experiences by participating and observing the lives and interactions of those they are studying. Within this latterly discussed epistemological framework, Casper and Talley (2005) have argued that as disability is lived experience ethnography is a particularly useful methodology.

In an often cited study, Edgerton and colleagues applied participant observation in a longitudinal study to understand people classified as learning disabled living in the community following deinstitutionalisation (Edgerton, 1993). Edgerton et al found that the service users had successful coping strategies by drawing on sympathetic social networks. In further methodological writings on their study Edgerton et al argued that participant observation was useful: '[p]articipant observation allows us to learn what [learning disabled] people actually do, as well as what they say they do, and it permits us to glimpse what meaning these activities have for them and those who know them.' (Edgerton et al, 1984; p503). As such when people are studied in their 'natural' social environments, as is the aim of ethnography, researchers understand better their strengths and coping mechanisms (Shaw and Gould, 2001; p139).

In summary, ethnography is a methodology that aims to attain subjective experiences through the researcher's immersion in the world of participants over time. The key method in ethnography is, therefore, participant observation, through which researchers combine other methods, and grasp the detail of lived experiences.

Combining qualitative methods through participant observation

Participant observation is recognised as the most important ethnographic method (Sanger, 1996) because it leads to a more holistic understanding of the phenomenon being researched: 'a long-term period of social immersion in a particular setting, from which is generated the totalising and holistic descriptive account – the 'ethnography of' the group being researched' (Mitchell, 2010; p2). Participant observation has therefore been found useful in research with people classified as learning disabled who may not communicate conventionally and whose views have to be inferred from their actions. For instance, in their five-year study of the parenting strategies of mothers classified as learning disabled, Traustadottir and Sigurjonsdottir employed participant observation. They noted that participant observation allowed them to develop rapport with the women in the study who were suspicious of professionals because of their concerns that their children would be taken into statutory care. Another reason was that 'some of the women were inarticulate and found it difficult to explain things in interviews. In such cases, observations and visits to their homes over an extended period were the best ways to learn about their lives' (Traustadottir and Sigurjonsdottir, 2008; p333).

The epistemological underpinnings of participant observation are changing. Previously, it was supposed that the researcher could be a 'fly on the wall' witnessing without impacting on people's lives (Angrosino and Perez, 2000). Expanding further

on the theme of epistemology Angrosino and de Perez (2000) enjoin researchers to conceptualise observation as a 'context of interaction' whereby 'ethnographic observers interact with or enter into a dialogic relationship with members of the group being studied' (p678). In a contribution to the discussion Hume and Mulcock (2004) encourage ethnographic researchers to be 'insiders out and outsiders in'. On this basis researchers should position themselves close enough to attain familiarity and build rapport whilst simultaneously keeping sufficient distance to preserve their professional role.

There are important methodological implications of this turn to interaction in the participant observation literature. Along with the general turn to subjectivity in the social sciences, ethnographers are required to account for their role in the ethnographic text and draw out how their presence contributed to the documented events. The corollary of this is the need for reflexivity – through reflexivity the researcher acknowledges that the ethnographic text is their point of view and not the sole 'truth' (Denzin, 1997). Another important implication of Angrosino and de Perez's notion of observation as 'context for interaction' is that researchers can regularly interview eyewitnesses. In this sense there is little requirement for formal interviews because interviews are intrinsic to (verbal) communication (Warren, 2001).

So, for instance, to understand the stigma of disability within a family, Taylor (2000) studied the Duke family using participant observation over a ten-year period. The Dukes are a big family; most of the immediate family and their social network have been assigned social categories including learning disability. Even though he studied the family for ten years, Taylor noted that 'I have never formally interviewed the Dukes but, rather, ask questions that seem appropriate at the time.' (p68). It is possible therefore in ethnographic studies to operate observations and interviews

simultaneously. Similarly a researcher may collect artefacts, documents, and other textual material pertinent to answering their study aims as they become involved in the activities of study participants.

The combination of methods during participant observation has been shown to be effective in studying social work organisations. Studies set in social work agencies have found that practice culture, frequent organisational changes, increasing computerisation, staff shortages, and high caseloads sometimes cause a disjuncture between professionals' espoused values and their actions (Broadhurst et al, 2010; Ellis, 2004; Herod and Lymbery, 2002; Rafferty and Steyaert, 2009; Shaw et al, 2009). During participant observation a researcher can sensitively ask professionals to explain the discrepancy between their explicated values and actions. Besides, social work agencies are complex and fast-paced, so being there and witnessing events enables researchers to grasp complexity. Furthermore the MCA is new so through participant observation a researcher can observe at first-hand its practice implications and how practitioners delineate the remit of the MCA amidst other policy imperatives.

Another reason why ethnography is suitable for an exploratory study (such as the practice implications of the MCA within complex organisations) or understanding lived experience is that ethnographic research can involve (re)focusing from the general to the particular. This 'funnel model' of ethnography (Fetterman, 1998) draws attention to case study methodology as another useful ethnographic strategy. Indeed Fox (2004, p312) argues that ethnography and case study methodology are synonymous: 'an ethnographic research project is a highly specific case study, made up of numerous, even smaller case studies and of the fastidiously detailed qualitative materials from which they evolve.' Picking up the discussion about case study research in the next section, I show how the methodology has been applied within

broader ethnographic research to provide focus and detail on a phenomenon. My discussion in the next section is from the reference point of Abrax, who was the unit of analysis in my case study fieldwork.

Embedding case study methodology into ethnography

My second phase of fieldwork was a case study of Abrax, a 19-year old British man of Greek ancestry. There are multiple definitions in the literature about what constitutes a case; however Tavory and Timmerman's definition is a useful summary:

there is some consensus that a case refers to the way in which the empirical observations in a study are not only 'ideographically' analysed as a unique occurrence but as an instance situated within a series – a sociological topic of interest, a unit in an empirical or theoretical whole.
(2009; p248)

Although applicable in both quantitative and qualitative research, case study research is advocated when a researcher is interested in 'how' and 'why' questions (Yin, 2009). Here the researcher focuses on one or few instances of the phenomenon with the purpose of understanding it holistically through gathering multiple sources of data such as documents, interviews and observations (Gillham, 2000). From the point of view that a case study is useful in gaining additional focus on a phenomenon, the research strategy can be embedded within an overall ethnographic project or, it could be a standalone project wrapped around ethnographic methods (Gomm, 2011).

One of the leading thinkers of case study research, Robert Stake, argued that a case study could be methodologically useful for intrinsic or instrumental purposes. In

the intrinsic use of a case study, the phenomenon is researched because in itself, the subject-matter is interesting. The instrumental deployment of a case study on the other hand allows the researcher to pursue their interest further ‘to provide insight into the question.’ (Stake, 1995; p3). Abrax’s life accorded with Stake’s exposition of the rationale for case studies. Abrax was an interesting case in so far as understanding his life would illuminate how the MCA’s legislative framework impacted on a service user living in supported accommodation. Beyond this, understanding Abrax’s unique situation would also conform to Stake’s exposition of case study strategy as instrumental. On meeting Abrax he demonstrated understanding of abstract concepts despite his classification as a service user with complex cognitive needs. On top of this, Abrax displayed one of the other yardsticks of capacity – choice – but he needed his carers to guess a list of his possible choices, read them back to him and ask him to confirm via ‘yes’ or ‘no’ sounds. At other times Abrax’s carers also had to interpret his gestures and sounds and they were his link to the external world. Moreover Abrax’s carers described themselves as ‘Africans’ and considered themselves to have different cultures to Abrax; this provoked curiosity about how their ethnic identity impacted on Abrax’s decision-making⁶. Therefore, a case study involving Abrax would throw into sharp focus how the MCA’s definition of capacity played out within different ethnic traditions. In this latter justification for using a case study approach, Yin (2009) who is also regarded a key thinker in case study research suggests that the method could be ‘revelatory’ (p48). Put together, the issues discussed in this section reinforced the need to consider breadth, focus, and detail. Consequently I embedded a case study of Abrax within the broader methodological framework of ethnography in my fieldwork (Gomm et al, 2000).

⁶ In the next chapter I discuss this topic in more detail

The discussion of methodology in this chapter also shows that, in ethnographic research, data analysis and collection are arguably synchronic. For example the argument by Becker (2009) that qualitative research is iterative is, at another level, a postulation about data analysis. The researcher has to sift through the data to understand where gaps are, and they have to manage the large amounts of data which is usually generated through ethnographic research. The researcher also has to pay attention to how they would represent themselves and the people that they have been studying. In the literature, it is argued that ethnography presents distinct challenges around data analysis and representation; these two issues are discussed in the second part of this chapter.

Part Two. Interpreting and representing ethnographic data

While data analysis and representation are pertinent issues in both qualitative and quantitative paradigms, in my study, they were amplified because my substantive concerns touch on my subjectivity. I am a black man living in a dominant white society exploring the theme of ethnicity (and culture). Besides I am a qualified social worker engaged in ethnographic research within the context of social care. As such I could be considered an 'insider' (Aguilar, 1981), a status which then raises questions about whether I maintained adequate 'distance' from the data in my analyses. However, in ethnography induction and subjectivity are methodological agendas; furthermore there is an ethical requirement for researchers to position themselves in the text. Some methodologists advise that ethnography researchers enter the field without any *a priori* conception of the likely outcome of data collection. It is advised that, taking an inductive approach, data analysis should proceed from the 'ground'

instead of from predefined coding frames (Hammersley and Atkinson, 2007). Here in Part Two, I start by discussing data analysis in ethnography as a context for exploring the theme of representing subjectivity in ethnographic research output.

Analysing ethnographic data

Qualitative research generally involves analysing texts – as Silverman (2000) argues, even if researchers use interview methods in their research, the voice recordings have to be transcribed into text which then becomes the focus of analysis. Various traditions in qualitative research have different approaches to analysis depending on research aims. For instance, researchers interested in the stories people tell about their lives would utilise narrative analysis to explore the content of individual accounts, or the construction of life histories within research contexts such as in interviews or observations (Cortazzi, 2001; Plummer, 2001; Reissman, 2001). As well as there being ‘tools for the job’ in data analysis, there are also various epistemological underpinnings. Some researchers, influenced by realism, would treat data as a window onto an independent world, whereas those inclined towards social constructionism or poststructuralism would consider data as evidencing the contestability of knowledge claims. In ethnographic research, debates about analytic strategies and epistemologies crystallise around grounded theory, which is regarded by leading methodologists as the primary technique for analysing ethnographic data (Charmaz, 2000; Charmaz and Mitchell, 2001; Hammersley and Atkinson, 2007). I expand on the theme of grounded theory further in the next section.

Grounded theory in ethnography

Terming it an ‘iterative-inductive approach’, O’Reilly (2005, p177) suggested that grounded theory data analysis is intrinsic to all aspects of ethnographic research. First

proposed by Glaser and Strauss (1967), and reformulated by its initial proponents and other writers, grounded theory retains the central tenet that data is collected and analysed inductively (Clarke, 2003). Strauss' succeeding work devised 'canons' for the application of grounded theory, which appeared to align grounded theory to principles of quantitative research (Corbin and Strauss, 1990), because researchers had to adhere to detailed formulae. Commenting on grounded theory, McCallin (2009) posited that Glaser's future work in contrast was less formulaic but it retained aspects of post-positivism and realism in that Glaser considered there to be an external world independent of the researcher.

In response to postmodernist challenges to the possibility of foundational knowledge, grounded theory has been reformulated. In 'Grounded Theory: Objectivist and Constructivist Methods', Charmaz developed a 'constructivist' approach to grounded theory underpinned by the theoretical position that '[d]ata do not provide a window on reality. Rather the "discovered" reality arises from the interactive process and its temporal, cultural, and structural contexts.' (Charmaz, 2000; p524). Charmaz also argued that her approach was akin to ethnographic research because she enjoined researchers to take an inductive approach. This allowed researchers to derive their findings from observations and interviews rather than deductively from pre-determined theoretical assumptions or coding frames.

Similarly Clarke (2003) proposed situational analysis. She advised researchers to follow three stages in analysis, which were intended to provide multiple perspectives on the phenomenon being researched. Situational analysis ostensibly responded to the postmodernist challenge to positivism by highlighting the divergent perspectives that create knowledge. Nevertheless by proposing a formula for data analysis, Clarke may be accused of circularity: she argued that there was only one

way of conducting situational analysis, which itself is a methodology geared towards attaining diversity in empirical data analysis.

Charmaz, on the other hand, can avoid the charge of circularity because she eschews a formula for her constructivist approach, and instead provides advice through her numerous writings on using grounded theory. For instance she advises line-by-line coding as a way of data familiarisation. Charmaz also argues convincingly that it is better to code using gerunds: 'Gerunds prompt thinking about actions - large and small. If you focus your coding on *actions*, you have ready grist for seeing sequences and making connections.' (Charmaz, 2006; p136; original emphasis). By gerunds, Charmaz is referring to words ending in 'ing' as in for instance: participating, assessing, reformulating. Whether coding according to gerunds or not, the key advice however is that researchers generate analytic codes inductively (Hammersley and Atkinson, 2007). In grounded theory it is also suggested that instead of being descriptive, coding should aim at generating new concepts (Holton, 2009). Additionally, creativity in data analysis, close attention to data, comparing and contrasting salient data, and (re)drafting emerging analytic ideas are emphasised (Charmaz, 2006).

Another interesting idea in ethnographic data analysis proposed by Brown (2011) is the use of the researcher's subjectivity. Brown, who described herself as 'a Black female researcher', studied racial discrimination in education with predominantly black students. She felt she had experienced discrimination and was therefore familiar with the subject matter. However, it was only away from the research site, paying close attention to data during analysis that the relevance of her life experience to the research became clearer. She noted that '[my] race took on a new impetus once I was out of the site. Pouring over mounds of observational and

interview data, I realised that race operated in hypervisible and invisible ways simultaneously for both the participants and me.’ (Brown, 2011; p106). Brown’s insight suggests, therefore, that the most useful point of the researcher’s subjectivity in the research may be during analysis of ethnographic data. More broadly, some writers have highlighted the methodological and ethical need for reflection in the ethnographic text (Tedlock, 2000).

Representing people and ‘I’ in ethnography

In my research it was important to reflect on how I had affected the outcome of fieldwork because I am a black man studying fellow ethnic minorities. I am also a social worker who conducted fieldwork within a statutory social work setting. Given my closeness to the subject matter of my research, there was the need for careful reflection on how I represented the data. Sometimes used interchangeably there is, however, a distinction between ethnographic writing and representation. Writing refers to the textual product of empirical research whereas representation encompasses other forms of exhibiting research output such as through films, performance, and poetry (Denzin, 1997; Sparkes, 2009). Some writers advocate canons for ethnographic textual representation. Atkinson (1990) suggests that ethnography texts require plausibility and authenticity: writers have to convince others of the topicality of the research, and their witnessing of the events described (indeed Atkinson’s advice is now recognised as applicable to qualitative research in general (Long and Godfrey, 2004)). Referring to the need for ethnography to persuade, Sanger (1996) enjoins researchers ‘to raise the consciousness of both those within and without the same circle, with regards to the issues, events and contexts of the study’ (p115).

Atkinson (1990) and Sanger (1996) were writing at a time of increasing attention to the nature of ethnographic textual representation. Van Maanen (1990) noted the consensus on the methodological ascendancy of participant observation but highlighted the epistemological and methodological unsustainability of the notion of the 'impartial' fieldworker producing unadulterated research. By 1995 Van Maanen had noted a 'shift toward text [which] is, of course, part of a much wider scholarly turn toward meaning and language wherein the relationship ordinarily held to obtain between a description and the object of such description is reversed' (p14). Now there is a consensus that, as well as describing the individuals in the study, the researcher needs to reveal themselves within the ethnographic text (Angrosino, 2008; Mitchell, 2010).

The debates about authors' subjectivity and its influence on research outcomes emanate from postmodernist challenges to the longstanding place of ethnography as a primary research methodology of anthropology, and the latter's association with colonialism. Faubion (2001) has charted the close association between anthropology and imperialism in which by studying the culture of 'the Other', researchers provided "impartial" justification for colonialism on the basis that "savages" needed "civilisation". Initially anthropology was predominantly practised by white, western Europeans studying other cultures. From the mid-1970's, through the challenge of postmodernism, ethnography underwent a 'crisis of representation' by which questions arose as to the ethical and methodological appropriateness of researching cultures which researchers (mostly white, western men) were unfamiliar with and sometimes sought to misrepresent (Denzin, 2002). Stemming from these debates, now there is a consensus that as well as describing the individuals in the study the researcher needs to reveal themselves within the ethnographic text as a means of

accountability. Partly, this agreement is also an acknowledgement of the impossibility of 'fly on the wall' research activity in which researchers do not impact on participants' lives.

Another aspect of the debates about researcher subjectivity is the increasing attention to native anthropology. Here some researchers argue that people from the same group are more qualified to understand that culture and they are more likely to portray it sympathetically. In the sociology literature, these debates have crystallised around the utility of insider research with several traditions in the qualitative paradigm arguing for the use of experiential knowledge. These qualitative research traditions include standpoint epistemologies in feminist research (Fawcett and Hearn, 2004), user/survivor-led research in mental health (Townend and Braithwaite, 2002; Turner and Beresford 2005), and the participatory or inclusive traditions in learning disability research (Atkinson, 2004; Atkinson, 2005; Walmsley and Johnson, 2003). Addressing political agendas, the body of work identified here argues that only those who share similar social experiences as research participants can tune into their life stories to accurately represent their marginalisation. Additionally, through sharing similar embodied experiences as study participants, researchers acquire more fruitful research data because they know what questions to address. Consequently advocates of insider research draw attention to the possibility of easier fieldwork rapport and trust because participants know that their substantive concerns are being addressed.

Perhaps imbued with a less political agenda than the body of work described above, Ochieng (2010), who also described herself 'Black African', interviewed families of similar origin. In the process she found to her surprise that mutual ethnic identities meant that she became a methodological tool: 'the interesting aspect of this analysis is how, as a researcher of African descent researching with families of

African descent, I became part of the research process.’ (p1727). Furthermore mutual social experiences meant that ‘the understandings and knowledge I gained from families during the course of data collection was influenced throughout the process by who I am.’ (p1728). Following Ochieng’s reflective tone, Serrant-Green (2002) argued that methodological advantages arise because being an ‘insider’, a black researcher quickly builds rapport and trust, leading to richer data. The emphasis on biography as methodologically useful, discussed here, crystallises predominantly around data gathering and analysis.

However, it has to be acknowledged that the use of the subjective ‘I’, who is a member of the group being studied risks reification of their culture as well as the ‘I’ engaged in reflective representation. For instance in the case of Ochieng above, she could be criticised for reifying the category ‘black’ by assuming that all Africans have the same experiences or that all Africans born in Africa share similar life experiences as Africans brought up in the UK. Not only this, Ochieng could be criticised for assuming that the ‘I’ is unchanging because she postulated that the ‘I’ which carried out the research was the same ‘I’ engaged in data analysis or representation. Furthermore, as has been argued by Caughey (2006), ‘[s]tudies of culture are usually orientated towards groups, institutions, and societies. They typically lose much of their power to explain individual lives through their reliance on generalisations about the allegedly shared cultural orientations of sets of people in a specific group or community.’ (page xi). Thus, apart from reifying the researcher’s subjectivity, Caughey’s point above suggests that insider research could also result in reification of culture. This is because, in an attempt to describe the culture of the group to which they belong or are researching, researchers may portray culture as fixed in time and

shared by every member of the group, when culture is perhaps more dynamic with different strands practised individually (Nayak, 2005).

Other scholars take issue with possible methodological drawbacks which may result from an insider or subjective approach. Atkinson (2006) has warned that one consequence of the author's subjectivity taking centre-stage of the research is that their biography is elevated above the methodological and theoretical rigour usually demanded of academic researchers. Moreover there is the risk of 'going native' in ethnography generally, and more specifically from (self)identifying with the group being researched. 'Going native' could include lack of attention to detail because the researcher assumes familiarity with the subject-matter of the research. Some researchers who have studied groups they identify with have reported conflicts of interest, issues of confidentiality, and distrust from some members of their community who doubt the benefits of research (Zubair, 2012). It may be concluded that while there are undoubted epistemological and methodological advantages from sharing similar experience as research participants, there are also potential drawbacks.

Altogether, the present discussion in Part Two shows that the epistemological debates around representation and data analysis are analogous to the debates about the epistemology of qualitative methodology. They therefore call for paradigmatic, methodological and theoretical consistency on the part of the researcher.

Conclusion

In this chapter, I have discussed the qualitative paradigm and ethnography in order to situate my research methodologically. Notwithstanding the on-going epistemological debates about qualitative research, there is a consensus around key tenets of the paradigm. It is agreed that qualitative research is particularly suitable for

understanding lived experience, exploring under-researched substantive areas, and garnering detailed data. Ethnography is generally regarded as a methodology which fulfils these requirements of qualitative research. Furthermore ethnography is also seen as a useful methodology because it is a creative approach, which enables researchers to start with a broad area and with time, focus on units or people who epitomise the phenomenon being explored. This ‘malleability’ of ethnography (Amit-Talia, 2001) makes it suitable to study professional practice in the use of the MCA, which as the literature review has shown, is currently under-researched. Moreover, little research has sought to understand the lived experience of a service user simultaneously classified as ethnically different and learning disabled, within the context of the MCA. Having taken the methodological issues outlined here into consideration in my research, in the following chapter, I discuss the ethnographic methods I employed to achieve my research aims.

CHAPTER FOUR. METHODS AND RELATIONS IN CONDUCTING FIELDWORK

Here in Chapter Four I provide a reflective account of my data collection methods. The chapter is divided into Parts One and Two, which respectively deal with both phases of my fieldwork in the integrated service and the case study with Abrax. For anonymity purposes I call the statutory service Kotoka and Abrax's supported living residence Yarlow.

Part One. Doing ethnography in Kotoka

I start Part One by explaining how I gained ethical approval and access to Kotoka, paying attention to how both impacted on my subsequent methodological practices. Then I discuss how I conducted observations, interviews, and data recording. Overall, I highlight in Part One the unexpected complexity of Kotoka whilst showing the exciting possibilities that existed for further recruitment of participants once I gained the trust of professionals.

Gaining access

In addition to gaps in the empirical literature I sited my research in statutory services for two reasons. Firstly, I envisaged that an institutional context would impact on the operationalisation of the MCA. Secondly, I formed the assumption that, with tightening eligibility criteria, learning disability service users were likely to have complex needs, thereby bringing them within the remit of the MCA. To adhere to the principle of inclusivity, I planned my thesis to involve persons who are not presented

with the opportunities to take part in research because of the complexities of eliciting their mental capacity to consent. Given this latter reason, I required clearance from an 'appropriate body', which is mandated under the MCA to ethically approve research involving incapacitated adults (DOH, undated)⁷. One such 'appropriate body' for research in social care settings is the Social Care Research Ethics Committee (SCREC). However according to my University regulations, I also required ethical approval from the Open University Human Research Ethics Committee (OUHREC) before applying to SCREC. Therefore by the time I approached local authorities for access, my research had undergone ethical clearance from two bodies (the OUHREC and SCREC).

On being granted ethical approval by SCREC in March 2011, I contacted London local authorities to involve social workers and service users. SCREC maintains a record of MCA research governance managers so I did not find it an onerous task identifying the relevant people to contact in each local authority. Most gatekeepers did not want to facilitate my study and several reasons were provided. An example was one gatekeeper who said that due to on-going organisational changes I would not be allowed access. Another gatekeeper considered my research 'interesting' though access could not be granted because '[access] would require a lot of input and support from our social work staff. They're currently very over-stretched and are unfortunately not able to work with you on this at this time.'⁸ Those managers who expressed an interest in facilitating my research did not respond in time to my emails and phone calls. Interestingly, although social work departments have a longstanding tradition of training students, the research governance managers I

⁷ < <http://www.screc.org.uk/files/mcafactsheet.pdf> > (accessed 12 June, 2013).

⁸ Personal email communication

approached appeared unfamiliar with academic research and PhDs in particular. This lack of awareness is another potential explanation for the difficulty in accessing local authority sites for research as noted by Munro et al (2005).

Once it became clear that I would struggle to gain access to local authority sites, I contacted a previous colleague (senior manager in disabled children's service) to make use of her professional contacts. She put me in touch with her colleague Chris – a senior manager in Adult Services – who did not initially respond to emails and telephone messages until I reached him early one morning. Even then Chris advised me to call the Assistant Manager of his team, Danielle, to arrange a meeting but this became another gatekeeping mechanism as I now had to negotiate access with Chris' intermediary. Nevertheless, in early April 2011, Danielle invited me to a team meeting to explain my research and in her words 'persuade' her colleagues to participate. As preparation for the meeting, I contacted a University researcher (one of the few researchers to have conducted empirical research with social workers since enactment of the MCA) and sought her advice on my presentation to the social work team.

I took the Information Sheets and Consent Forms that I prepared for the SCREC review to the meeting with social workers. Instead of the 18 professionals Danielle said would attend the meeting, there were only six. Also I learnt that I had been allocated 10 minutes at the beginning of the meeting for my presentation. Mindful of the entrenched audit culture in social work practices (Saario and Stepney, 2009) I sought to convince professionals that my research was not primarily an evaluation of practice. Instead I highlighted that my fieldwork aimed to understand practice under the MCA by 'shadowing' social workers in their routine activities. I also told the professionals that I hoped to recruit some of the service users on their

case loads for the second phase of my research. At the end of my presentation the lower than expected attendance for the meeting and what looked to me to be disinterested professionals convinced me that there would be no volunteers for the study. As such, I was surprised to hear from Danielle that eight social care professionals had volunteered for the research, meaning that more staff had volunteered for the study than attended my presentation. In further email correspondence with Danielle, we agreed that I would start fieldwork on 06 June 2011.

I envisaged that the core participants of my research would include the aforementioned eight social care staff. However on the first day of fieldwork one person withdrew on account that she was leaving the team after a period of secondment. Thus there were seven core participants of my fieldwork, and others that I recruited when data collection began. Of the core participants, there were respectively five women who described themselves to me as ethnic minorities (Ofira, Audrey, Mavis, Annika, and Adwoa) and one white woman (Rose). There was only one male core participant (Shane) and he described himself as British of Grenadian origin. Shane did not have a social work qualification and he had specified duties of liaising and assessing carers. My reflective account here about gaining access to Kotoka and ethical approval from SCREC sets the scene to discuss in the next section, how the two events impacted on my research.

Reflections on the methodological impact of negotiating access

A key part of my application to SCREC was completion of the Integrated Research Application System (IRAS) form on which I had to identify risks to participants and how I would address them in fieldwork. At the time of applying to SCREC, I did not

know the setting of my research therefore I had to imagine the potential research site. In the event I envisaged a discrete social work team. I also made a 'non-interference' commitment on my IRAS form, indicating that as far as possible my research would not 'interfere' with the work of the social work team. I also said on the IRAS form that I would shadow each social worker for one hour at a time on alternative weeks.

Besides the 'non-interference' commitment I made two key methodological decisions before fieldwork commenced. Firstly, I emphasised to core research participants that instead of distinct events I wanted to observe 'routine' activities. Having been a social worker and thus aware of the unpredictable nature of practice, I reasoned that any attempt on my part to witness specific practice issues would be superseded by events. Nevertheless, by telling social workers that I wanted to observe their 'routine' activities, the substantive focus of my research changed inadvertently. Instead of solely focusing on mental capacity assessments my research aims broadened into how professionals drew upon the MCA and accompanying statutory requirements in practice. Secondly, before fieldwork commenced, I sent professionals a schedule of my shadowing days. My intention was to alternate the days and times of shadowing: so for instance if I observed social worker A on Monday afternoon, in the following week, I would shadow them on a Tuesday morning. The schedule was a strategy I devised to allow me study practices at separate times, thereby facilitating my understanding of the rhythm of the team (Hammersley and Atkinson, 2007).

Interestingly, the question as to whether an ethnographer should have a fixed research schedule prior to fieldwork is a matter of heated contention in the methodology literature. Some writers imply that the researcher should approach the fieldwork site with no prior conception, and upon familiarisation, orientate the research towards relevant questions. Amit-Talia (2000) for instance, argues that the

boundary of the 'field' is difficult to draw - the inference here is that the researcher may not have a schedule until starting the research. On the other hand, Hammersley and Atkinson (2007) advice researchers to 'case' the site and pilot their study before fieldwork, so on this measure, one could have an itinerary. In my case, I found that the prior schedule worked well because the social workers noted the dates in their diaries and set time aside for me to shadow them.

Overall, the process of seeking ethical approval and negotiating access had unintended consequences. Iversen (2009) noted that 'getting out' of fieldwork could be fraught with ethical complications, however these were minimised in my case. The social workers knew from the outset what I would be doing and the approximate date for completion of my fieldwork. By corollary, I also told them that there was a planned second phase of fieldwork for which I would involve some of the service users on their case load. A less positive by-product of gaining ethical approval was that my commitments to SCREC sometimes circumscribed my fieldwork creativity. On some occasions I declined invitations to conduct unscheduled observations as I believed that these unplanned appointments were against my commitments to SCREC. Equally importantly, because by the time of applying for ethical approval I did not know where my research would be sited, I constructed a fieldwork context in my mind. Thus one consequence of seeking ethical approval was that I inadvertently designed research for a bounded research site with sequential work processes, entirely different from what I encountered. I now expand further on my data gathering methods in Kotoka.

Gathering data in Kotoka

On my first day in Kotoka, it became clear that the research site was far more unbounded and complex than I envisaged. Whereas in my application to SCREC I

imagined an independent social work team, Kotoka was an 'integrated service' comprised of discrete teams of professionals including: social workers, occupational therapist, speech and language therapists, nurses, psychiatrists, and psychologists. Each team was supported by administrative staff. In conversations with staff on my first day of fieldwork, I realised I could recruit other professionals for the study. Returning home after my first observation, I noted in my Reflective Diary⁹ the unexpected complexity of the research site and the concomitant need for me to quickly decide on the direction of fieldwork:

I observed far more people and events than I ever imagined would be the case and there is so much more that goes on in [the] office than I ever imagined would be the case [...] There are so many possible sources of enquiry so I have to pretty much make my mind up quickly about which one I am going to follow. This is especially the case because the team is 'integrated' and now that I have access it seems that I can pretty much include any professional other than social workers. (Reflective Diary 08 June 2011).

One noticeable consequence of service integration was that, in contrast to my prior conception, Kotoka received referrals and made referrals in turn. Moreover professionals from Kotoka worked closely with several teams within the local authority, with important consequences for my substantive interests. These issues

⁹ During fieldwork I kept a Reflective Diary in which I recorded daily my reflections. I wrote in a more contemplative voice in the Reflective Diary.

outlined here showed the need to include more professionals and teams beyond the core participants.

Observing events and practices

Primarily I designed my research as non-participant observation because of the ‘non-interference’ commitment I gave to SCREC. I refrained from engaging in any activity liable to be interpreted as ‘doing social work’. In part my non-participant approach was aided by the fieldwork schedule I sent to social workers prior to commencing the study. Ostensibly, whilst I was engaged in shadowing one professional the rhythm of the team did not concern us although, in practice, each period of observing one professional was punctuated by their receiving phone calls, taking messages for colleagues, talking across the room to a colleague, engaging in informal case management, and navigating the complex information technology system. Also I did not have a rigid framework for observations: I observed people and events after appraising previously collected data, or I observed chance events which seemed of direct relevance to my research.

Consequently, my observations moved between the general and the particular. In the first few weeks I concentrated on understanding the remit of the integrated service, work process, inter and intra team relations, and the personalities involved in my research. Opportunities also arose for me to focus on particular events such as assessments, service user/professional relations, and duty tasks. Sometimes I practised focused and general observations in the same shadowing session. Realising that the research site was more complex than I had envisaged, at the beginning of each shadowing session I made a rapid analysis of whether to engage in focused or broad observations. These analyses were helped by the fact that professionals explained what they were doing on each shadowing session, and because I observed each person

a few times, they compared and contrasted the present observation with previous ones. Where it was clear that I would be encountering a new event I engaged in broad observation and I employed focused observations where there was a repeated event.

At other times, I did not observe anyone or anything in particular. I arrived early for some shadowing sessions to hang-out in the reception area to gain a sense of which service users made unscheduled visits to the office. I obtained valuable data sitting in the reception area making notes of the ethnic identity and gender of visitors to the office. In order to become familiar with the professionals I also sometimes sat in the staff kitchen during lunch time to ask questions and answer some in turn or just to get a sense of relations between staff. The observation method I have described here contrasts with Fetterman's funnel model (Fetterman, 1998; p35) which starts with 'uncontrolled and haphazard' observation and culminates in a more focused observation of issues pertinent to the research question.

I found that I engaged in data analysis as fieldwork ebbed and flowed. In the ethnography literature it is often implied that research is a linear process starting with research design, fieldwork, and then data analysis. A notable departure is Candea (2009) who, in describing his fieldwork in Corsica, argued that fieldwork and data analysis are synchronic if only as a way of substantively delineating the research. In my case, due to the unexpected complexity of the research site, it became part of my fieldwork routine to read over previous notes, making methodological decisions about which areas of the organisation and what people to include in subsequent observations. One other notable feature of fieldwork in Kotoka was that most professionals refused me consent to tape interviews so my routine conversations acquired the status of interview data.

Interviewing in Kotoka

Methodologically, I had to make sense of the organisational remit and work processes of Kotoka -to achieve this aim, I was inspired by institutional ethnography: '*Institution*, in this usage, does not refer to a particular type of organisation; rather it is meant to inform a project of empirical enquiry, directing the researcher's attention to coordinated and intersecting work processes taking place in multiple sites' (DeVault and McCoy, 2002; p753; original emphasis). DeVault and McCoy expanded further that the researcher employing institutional ethnography need not have formal interview schedules or a prior idea of whom to interview. Building on incremental knowledge, the 'informants are chosen as the research progresses [...] each interview provides an opportunity for the researcher to learn about a particular piece of the extended chain, to check the developing picture of the coordinative process, and to become aware of additional questions that need attention' (p757). I determined who to interview from my discussions with the core participants. For instance I learnt that there was a Person-Centred Planning (PCP) Coordinator whose role was to help service users make decisions during key transition points in their lives. Because this task involved eliciting decisions from service users, I felt that substantively, it had relevance to my research. I therefore interviewed the PCP Coordinator.

As fieldwork evolved I gained a greater understanding of the complexity of the research site and salient issues. It was clear that the concept 'safeguarding' occupied a special place in the psyche of the professionals and impacted on their interpretation of the MCA. Realising that there was a separate team in charge of Safeguarding Adults policy and procedures, I sought and gained three taped-interviews. One interview was with Emma, the deputy manager of the team. I also conducted two interviews with the team manager Abby (Abby's duties included

recruitment and training of Best Interest Assessors¹⁰). Both Abby and Emma were female and I would describe their ethnicity as white. Abby was from South Africa and considered herself an ethnic minority in the UK. Reflecting on her experiences in the UK she felt that she had been discriminated against because of her accent. Abby, therefore, identified with the substantive concerns of my research and was keen to facilitate access to other professionals.

Abby put me in touch with two female occupational therapists who were also trained Best Interest Assessors. One was Jo, a team manager, and she agreed to be tape recorded. The other professional, Patience, was an occupational therapist and did not agree to be tape recorded. In the interview Patience appeared reticent, prompting me to make the following notes in my Reflective Diary:

When Patience arrived and we went into the office and we sat down she told me that she did not want to be tape recorded. Sitting here now I recall that as soon as she said that I had a premonition that the interview would be difficult. (Reflective Diary, 2 August, 2011).

The exchange with Patience recorded in my Reflective Diary neatly captured professionals' reluctance to being tape recorded. By an unfortunate co-incidence, I commenced fieldwork in the same week that covertly obtained film footage of residential care workers abusing learning disabled service users was shown on

¹⁰ In the MCA, Best Interest Assessors determine whether any action by professionals on behalf of service users lacking mental capacity is in their 'best interest' (DCA, 2007).

Panorama, a prime-time current affairs programme¹¹. Perhaps as a result of the Panorama programme none of the core participants consented to being taped recorded; this also encapsulated the general mood of mistrust that my presence sometimes generated. On some occasions people indicated that they were uncomfortable that I was taking notes. At another multidisciplinary meeting, a senior manager asked the Head of Service whether my bag had been searched to confirm that I was not secretly taping the discussions.

On the rare occasions that professionals agreed to be taped, there was a palpable sense of tensions being released once I stopped the tape recorder. Of methodological importance, professionals appeared to interpret the tape being turned off as a signal that the formal interview was over; prompting them to reveal more than when the recorder was on. In the case of Patience, whose interview was not tape recorded, one way that I overcame her reticence was to make the interview less formal. I informed her of my ethical commitment to confidentiality as way of assuring her that all the information she gave would not be divulged to other parties¹², and that she could terminate the interview at any time. I also stopped taking notes. It was only after Patience felt reassured that she disclosed that in one case that she was involved in, managers had proposed a mental capacity assessment of a service user in order to prevent her parents from accessing her case files. According to Patience, MCA assessments were, therefore, used to 'silence' service users.

¹¹ The TV programme Panorama is broadcast by the BBC (British Broadcasting Corporation). As a result of Panorama's investigations, the Government published 'Transforming Care' (DOH, 2012) addressing concerns raised by the television programme. That the government responded with an enquiry evidences the political impact of the Panorama report.

¹² With the caveat that unless she told me that she had harmed a service user or someone was in danger.

Because of the limited consent given for me to tape record, I conducted informal interviews during shadowing sessions. The ethnography literature is in any case divided on the status of formal interviews. As explained above, in his ten year ethnography of a family, Taylor (2000) for instance took his routine interactions with the family as 'interviewing'. Forsey (2008, p59), on the other hand, argued that 'those being researched may even expect the researcher to employ such a tool [interviewing] as part of the investigation, an interview becomes part of the act of participant observation.'

Most of my interviews were also unstructured in that I did not have any prior questions or categories (Fontana and Frey, 2005). The nature of the questions I asked, however, changed in the course of fieldwork as I gained more information, developed rapport, and became familiar with the setting. Initially the questions were general, such as 'tell me about cases where capacity assessments have been conducted.' With time they became more specific: 'last time you told me about service user X and you said you did Y, could you explain more?' Moreover I considered all my routine conversations with professionals as interview data largely because I took the opportunity of each encounter to discuss substantive concerns of my research.

To sum up this section, once fieldwork commenced, it became clear that I could involve professionals besides social workers in my research. I decided whom to recruit for the research on the basis of what other professionals told me about the work of Kotoka as well as my previous observations. In the main, I found it easy obtaining interviews, however because my fieldwork coincided with the Panorama documentary programme on the abuse of learning disability service users, my presence elicited mistrust. As people were reticent about me tape recording interviews, note-taking and field notes became central to my data collection.

Note-taking and field notes

I conceptualised field notes as the texts of unfolding events that I handwrote in a book whilst in the field. I make this clarification because notwithstanding their longstanding association with ethnographic research, there are debates about the nature of field notes, when they should be written, and how they should be organised. In their review of the literature on field notes, Emerson et al (2001) explained that some researchers distinguish between their recordings of what was observed in the field and their reflections, whilst others consider the two together as field notes. In my fieldwork I opted to consider field notes as my records of events in the field so from the outset, I envisaged that the field notes would be the primary focus of my data analysis. So during observations I made detailed notes which I later transcribed using my computer (Walford, 2009). I also kept a Reflective Diary in which I recorded my thoughts, uncertainties, and new lines of enquiry. Finally I kept electronic memos in which I wrote my emerging thoughts on concepts, theories, or analytic threads (Charmaz, 2006). Thus while I kept the Reflective Diary and memos to enable me keep track of my evolving substantive ideas and changing emotions, my field notes were written with their role as the centre-piece of my data analysis in mind.

I made field note entries immediately after each period of observation. The nature of my note-taking changed with time. In his discussion of field notes in ethnography, Wolfinger (2002) proposed two methods for writing field notes: 'the salience hierarchy' in which researchers document their observations in order of importance, or the 'comprehensive', in which they 'systematically and comprehensively describe everything that happened during a particular period of time, such as a single trip to the field.' (p90). Early in fieldwork I took 'comprehensive' field notes: I recorded events chronologically, sequentially and in minute detail.

Whereas before fieldwork I felt that my prior experience as a social worker would help in observations, I was taken aback by the pace of activity in Kotoka. Therefore at the beginning of fieldwork I felt that I needed to capture every event. At other points my note-taking was underscored by some key assumptions. For instance when I observed a multidisciplinary meeting, I noted my observations of unfolding events sequentially because I felt that the interactional patterns revealed power hierarchies.

On some occasions I could tell that taking notes interrupted the flow of conversation or I could feel a palpable sense of unease in the room because of my note-taking. In all these instances where I did not take notes at the time of observation, I used substantive issues from the meeting (or observations) to jog my memory or, sometimes, I tried to recall the conversations or observations in chronological order. On my way home I would make additional notes on the train with the view to immediate transcription.

Given the reliance on recall described above, I agree with the assertion by Emerson (1995) that field notes are constructions. On the one hand, my agreement with Emerson is partly due to my paradigmatic affiliation to social constructionism, which entails the researcher taking a reflexive stance towards epistemological and ontological claims about 'reality'. On the other hand, my agreement stems from the experience of writing field notes. Often, even after transcribing immediately after observations, I found that I could not be certain of my recollections. On other occasions, my recollection of events contradicted the notes I made at the time of the observations. Occasionally, my on-going transcriptions clarified previous notes and I would return to those documents to annotate. I found periodically that writing notes gave me ideas about questions to ask and events to observe in the next fieldwork encounter. In this later sense, it may be said that the present influenced future data

capture which then played back to my past understandings. Apart from transcriptions, another way that the present interplayed with the future was that I was able to recruit for the second phase of fieldwork whilst in Kotoka. This was an undertaking given on my SCREC form, so as my ethnographic fieldwork in Kotoka evolved, I was simultaneously planning for fieldwork with service users.

In the current discussion of my fieldwork I have focused on my data collection methods in Kotoka, a local authority research site. I explained that I required ethical approval from SCREC even before I could approach local authorities. Once SCREC approved my research I contacted local authorities for access; however, in the end I had to make use of personal contacts to gain access to Kotoka. The process of negotiating access (seeking ethical approval and using personal contacts) impacted on my fieldwork practices because I made commitments which later restricted some fieldwork creativity. However an advantage of the ethical approval process, on the other hand, was that I committed to recruit service users through Kotoka; therefore, I could simultaneously plan for the fieldwork with service users alongside my observation of social care professionals.

Part Two. Case study research with Abrax in Yarlow

Part of the planning for the second phase of fieldwork involved asking social workers to identify service users who I could involve in my research. Towards the end of my time in Kotoka, I asked them to introduce me to ethnic minority service users on their case loads. The first person I was introduced to was Abrax who his social worker described as an ethnic minority. Abrax's social worker also told me that she had permission from Abrax's parents for me to approach him for recruitment purposes. In order to meet Abrax, I sought prior authorisation from a gatekeeper, a senior manager

of the private agency which owned Yarlow. Expanding on the theme of a case study approach, in Part Two, I discuss the rationale behind my methodological move, how I designed the case study, and the methods I used to collect case study data. One advantage of the two phased nature of my fieldwork was that, by the time I became acquainted with Abrax, I was a more confident researcher, having in one sense practised the methodology in Kotoka.

Constructing Abrax as a unit of analysis

Abrax was the unit of observation and analysis of the case study. I focused on the following social contexts: his family relations, his interactions with his care workers in Yarlow, and his everyday life. Because Abrax was provided with 24-hour care by five African men, they also featured prominently in the case study. A case study methodology applied in Abrax's circumstances for a number of reasons. Returning briefly to my discussions on methodology (Chapter Three) a case study is advised if the following factors hold: the case is a substantive research concern and the researcher seeks 'breadth' and 'depth' of a phenomenon (Stake, 1995). Abrax was a central concern of my research which aimed to explore how an ethnic minority learning disability service user made decisions in their everyday life. Furthermore, the MCA identifies learning disability as a condition which could impede mental capacity. Additionally, as Abrax lived in supported accommodation, the MCA required a consideration of his mental capacity to consent to changes in his place of living (Harker, 2012).

Beyond substantive interests, Abrax was unique in my view. Although Abrax was classified as learning disabled he was believed to have capacity to make decisions for himself. On this latter point, Abrax was a deviation from folk understandings of learning disability. Abrax's ability to understand and yet not vocalise his thoughts

also stood out as a deviation from the MCA's stipulation that one yardstick of mental capacity was an ability to 'communicate'. Furthermore, Abrax was a British national of Greek-Cypriot origin, nevertheless he was considered ethnically different by a social worker. Abrax was unique: therefore, I felt that a case study would provide deeper understanding about the interaction between ethnicity, mental capacity, and learning disability in everyday life.

The discussion to date suggests that it was possible to delineate the case. In the methodology literature much is made about the need for a case to be 'bounded', by which it is meant that the phenomenon under study should have defined boundaries (Brown, 2008). However I am unconvinced by the latter advice. Epistemologically, one cannot define the boundaries of the case primarily because they are temporally and spatially unstable (Verschuren, 2003). In Abrax's situation for instance, it was not epistemologically sustainable for me to conceive of him outside the network of his paid carers or his family. This is because Abrax's social network formed his link to the outside world by (re)interpreting his sounds and gestures to other people. Nevertheless I followed the advice of Stake (2005) that it was necessary to define Abrax as the case for conceptual and analytic purposes, if only as a way of delineating the boundaries of my research. As it happened, with Abrax, the focus on him and his immediate social network of his family and the private agency constituted his 'everyday life': 'The term 'everyday' or 'everyday life' refers to the immediate environment in which a person carries out the specific tasks associated with home life, employment, leisure etc.' (Lewis, 1997; p43).

Although I embedded the case study of Abrax within a broader ethnographic methodology, there were differences between fieldwork in Yarlow and Kotoka. The activities and individuals in Yarlow were clearly defined. Unlike Kotoka which

proved more complex than envisaged, from the outset, I identified Abrax as the unit of analysis; therefore I had a focus for the case study. Besides, I knew who to speak to in Yarlow about Abrax's needs. On the other hand, in Yarlow I had to focus more on minutiae than in Kotoka because Abrax did not communicate in sentences but through gestures and monosyllabic sounds.

Collecting case study data

As part of the case study I spent time with Abrax at home, in the community, and the day centre at different times. Furthermore I interviewed Abrax's parents in their home and I had several telephone conversations with them. This ethnographic data was augmented by interviews I conducted with five of Abrax's support workers, professionals in the day care centre and an occupational therapist who previously assessed Abrax's mental capacity for employment. Finally, I collected documents including records made by each support worker after the end of their shift with Abrax. In this section, I expand on case study methods, starting with observations.

Observing Abrax and his social network

My first three visits to Yarlow were to fulfil the ethical requirement to assess Abrax's mental capacity to consent to participate in my study¹³. In my application to SCREC, I gave an undertaking to assess service users' capacity to consent after visiting them at least three times. The MCA stipulates that an assessor should 'objectively' measure mental capacity. However, I felt that a more ethically robust approach would be for me to understand Abrax's communication needs and his personality first before assessing his capacity to consent. Consequently, reflecting the overarching

¹³ In Chapter Eight I explain further how I assessed Abrax's mental capacity.

ethnographic methodology of my study, in order to understand Abrax's life in a broad sense, I gathered as much information as possible on the first three visits. Early in fieldwork with Abrax, to become accustomed to his unique communication methods I sought advice from his parents and support workers about interpretations of his gestures and sounds. Due to the procedures explained here, by the time I assessed Abrax's capacity, I broadly understood him, and I had also gathered detailed information about his life.

In the case study of Abrax, emphases changed over time or even per observation, oscillating between the particular and the general (Merriam, 1988). These aforementioned decisions were influenced by what was happening around me at the time or whether the observation had been pre-arranged with Abrax and his carers. For instance, if an observation was pre-scheduled I would decide beforehand whether it was the first time that I was witnessing Abrax engage in that activity. By chance sometimes I observed rare events with important consequences for Abrax. An example was when I accompanied him to attend a physiotherapist clinic in his old school, Marigold, for his yearly fittings of new splints. Visiting Marigold offered the opportunity to interview school staff who knew Abrax since childhood and could, therefore, explain some epiphanic moments in his life. Additionally, I observed Abrax's interactions with his former peers, the reception accorded him by non-academic staff and his facial expressions within a familiar but infrequently accessed space.

Mainly, however, I set out on my visits to Abrax to observe minutiae. For instance when I saw Abrax for the second time, the look on his face, his stretching out his hand to touch my arm, together with the noise that he made indicated that he remembered me from my first visit. Even on the first visit Abrax could indicate that

he knew that I was the person whose photo was on the Participant Information Sheet. It seemed to me that Abrax displayed high cognitive capacity in the recognition of faces, thus my quest was to capture data on those moments when he displayed his understanding. Each day of observations, therefore, focused on how, for instance, Abrax displayed recognition, how his carers elicited responses from him, what kinds of questions his carers asked him in order to evoke responses, and how Abrax indicated that his carers had (not) understood him.

In addition to minutiae, I also observed the broad strands of Abrax's life in order to understand his daily routines. To this end I asked about rituals at key points of the day such as meal times, his personal care, how he dressed, and how he mobilised using his wheel chair. Recognising that people also live their culture through the artefacts in their homes (Caughey, 2006), I observed the surrounding environment, Abrax's rooms, and even the clothes he wore. On several occasions I accompanied Abrax and his support workers to a day centre where I observed how he associated with his peers and professionals. Abrax had physiotherapy sessions every Friday in the day centre so, with his permission, I observed his exercise routine. Like the fieldwork with social workers my conversations with professionals constituted interview data; however, I also conducted some tape recorded interviews. In the next section I expand on my interview methods during the case study, starting with interviewing Abrax.

Interviewing in Yarlow

Drawn to the principle of inclusivity, although I knew Abrax communicated mainly through monosyllabic sounds and gestures I sought to interview him whenever possible. Like Booth and Booth I believed that Abrax's means of communicating placed the onus on me to 'work harder (by having to ask more questions and probe

more fully to elicit information), but also pay more regard to the form of the questions, the sort of language used and the conduct of the interview' (Booth and Booth, 1996; p60). As Abrax responded predominantly to closed questions, I asked his permission about times to visit, whether I could accompany him on trips, and if he understood me. Sometimes Abrax and I attempted to communicate using his Communication Book; however, this frustrated Abrax because, with challenging fine motor skills, it was difficult for him to press the corresponding pictures on the Book. All these issues outlined above meant that, to understand epiphanic moments in Abrax's life, I had to interview his support workers and parents, an approach used by Hewitt (2000) during her work with people she described as 'hav[ing] the most profound physical and intellectual disabilities' (p95). Also because Abrax did not communicate in sentences, I played a greater part in constructing the data than envisaged. For instance, rather than their being explicitly stated, I inferred Abrax's views from his movements and sounds. Additionally I took the views of those who knew Abrax better than I did such as his parents.

Interviewing Abrax's parents

Abrax's parents played dual roles of consultees and informants in my research. According to the MCA requirements, in social research, consultees should be appointed if prospective participants do not have capacity to consent to their involvement (Davies et al, 2010; Dixon-Woods and Angell, 2009; DOH, 2008). Consultees are required by statute to advise researchers as to whether people with mental capacity-impeding conditions should be involved in empirical studies. Therefore, after deciding that Abrax could not consent to his participation, I appointed his parents as consultees to seek their advice, and this metamorphosed into subsequent life story interviews about him. In my encounters with Abrax's parents, I was guided

by the principle that they should both be present at every meeting and interview. Firstly, this was due to my ethical draw to transparency; that they should both hear the details about the research simultaneously. Similarly, I wanted to hear their first-hand accounts at the same time. Reflecting on my social work experience, I knew that parents' stories of their encounters with professionals sometimes contained painful stories. These narratives revolved around the fraught process of their children being categorised as 'disabled' for the first time or experiences of resource rationing. Thus, aside from transparency, I felt that both of Abrax's parents needed to be present at interviews to provide mutual support as they recounted his life experiences.

At the first meeting with Abrax's parents, as well as appointing them as consultees, I also piloted some life story interview questions. Abrax's parents agreed to a subsequent formal tape recorded interview at which I asked them about key moments in Abrax's life (Gibson, 2011). The second interview with his parents was more akin to a formal research interview. I had a tape-recorder and a note book. I asked new questions about Abrax's life history or asked his parents to clarify information given in the first interview. However, deliberately, I did not have an interview schedule. I thought that with Abrax having been known to statutory services for most of his life, his family would have been subject to numerous formal assessments. To avoid replicating the scenario of statutory assessments, I thought that I needed to adopt a conversational tone for the life story interview, and this would be achieved without an interview schedule. Subsequently, I transcribed the tape recorded interview. I also recorded telephone conversations with Abrax's parents as data, and these were transcribed and analysed.

Interviewing support workers

Abrax's support workers consented to being tape-recorded. However, usually, they were busy attending to Abrax's needs so I had to interview them informally as per my fieldwork in Kotoka. I formally interviewed one support worker on two separate occasions for about an hour each time and another support worker once. Similarly adopting a life story approach, all the interviews of support workers involved them explaining to me their culture and its impact on their work with Abrax. From the outset, my identities as a PhD researcher and a black African male of Ghanaian origin who held a British passport influenced fieldwork more than I envisaged. The support workers being black African identified with me. In interviews and observations the support workers used me as a reference point for their answers. In turn, I deliberately drew on my life history to mould conversations, explain my point, or build rapport. At other times, my life experiences gave me the intuition to pursue certain angles of questioning.

Contrastingly, at other periods in fieldwork, I felt that I instinctively understood certain events or stories and as a result did not pursue or query them further. The issues I identify here are hotly debated in the sociology literature as (de)merits of insider/outsider research or native anthropology (Ganga and Scott, 2006; Messerschmidt, 1981; Mizock et al, 2011). In accordance with my methodological position to reveal my role and (re)present 'I' (as discussed in the literature review, Chapter Two), I explore further the role of my identity in Chapter Eight.

Note-taking and document collection

During fieldwork in Yarlow I took notes and kept the same electronic templates as Kotoka. However, in Yarlow, unlike in Kotoka, I had the opportunity to collect

documents. I needed to know what had been written about Abrax. I asked for two types of document and was allowed to photo copy about two months' recordings of each. One document was a record of Abrax's daily activities, whilst another was the carers' notes of events through the night: for instance what time Abrax was helped to the toilet, whether he woke up at night unprompted, and his morning routines.

Analysing fieldwork data

My research has been guided by a grounded theory analysis for epistemological and theoretical reasons. Epistemologically, I have been drawn to an inductive approach to the data gathering. Firstly, my research area is relatively new, therefore, there was little material to refer to. Secondly I wanted to gain a broad perspective and understand complexity; I felt that any prior determination of issues to focus on during fieldwork would work against gaining some new directions in my substantive area. Due to these epistemological and theoretical positions I opted for a grounded theory approach to collecting and analysing data. As such, when I started fieldwork in Kotoka and Yarlow I did not have any pre-conceptions about phenomena requiring my focus, and I observed and made notes about everything happening around me. With time however, as a matter of practicality, I realised that I needed a framework to organise the data, if only for data management purposes.

Fieldwork data handling and coding

In order to compartmentalise my data, during the first phase of fieldwork in Kotoka I bore in mind three possible analytic strands - team tasks, professional decision-making, and service user needs – that interacted in complex ways for mental capacity issues to arise. However, at the same time, I reflexively held on to my theoretical position that team tasks, professional decision-making, and service user needs did not

have static conceptual boundaries: they were predominantly analytic frameworks for thinking about and keeping a bird's-eye view of my data. Then, using the computer programme Nvivo, I created electronic folders in which data pertaining to these three analytic threads would be stored. I continued with this data management strategy in Yarlow: thus the three electronic documents that I used for field notes (discussed earlier in this chapter) were later stored into Nvivo so that I could sort through documents, rename them, and break them down for coding with relative ease (Hutchison et al, 2010).

My approach to coding was predominantly influenced by Charmaz (2006) and Hammersley and Atkinson (2007). In the main my codes were derived from my data with an initial emphasis on understanding the content of the field notes. Following Charmaz especially, I have coded using gerunds: my codes are mostly words that invoke images of action and end in 'ing' – for example 'participating', 'setting the terms of engagement'; and 'reconceptualising practice issues'. While most of the codes emanate from my data others have been attained from my epistemological positions. So, for instance, I created the code 'drawing on culture' which is my theoretical position that rather than being static or identifiable, people draw on culture to make claims against the State.

In my earlier discussion of field notes, I explained that I wrote memos regularly to keep track of my ideas during fieldwork - I maintained this strategy with respect to data analysis. Thus in addition to coding data, I also engaged in frequent memoing of conceptual categories. As I grouped similar codes into categories (Holton, 2010), at key points, these sparked conceptual ideas which I memoed. One example of my analytic memos is presented below:

The concept (node) telling information to service user may be inversely related to assessing capacity. In other words where professionals find that the service user has the mental capacity to challenge their views or not follow what they are being told it becomes more pertinent to 'tell' them information: to present it as a *fait accompli* (Memo, 04 October 2011).

As well as illustrating my memoing, the data extract above also shows that I engaged in comparing codes – in the literature this is referred to as the constant comparative method (Holton, 2009). I examined the conceptual differences and similarities between my codes, which I memoed, then I examined the data and compared the actual incidents from which I had derived the codes. I found that, with time, I was not generating additional codes.

My strategy for data analysis was not a sequential process. I started analysing data whilst at Kotoka because even when I transcribed field notes, I made detailed annotations expanding on my observations and placing reminders about future issues to look out for. By the time that I started at Yarlow I was confident in my data analysis strategy but I found that I returned to the data I gathered in Kotoka to clarify the codes or change them. As a matter of epistemology I have also taken advice from Lather (2011) that data analysis is always in the process of completion so that researchers gain new understandings from re-analysing data. In the main the data that I have selected for my empirical sections in the thesis (Chapters Five, Six, and Seven) are those that best illustrate the phenomena I witnessed in fieldwork.

Conclusion

In this chapter, I have shown how I implemented my broad methodological framework of ethnography in fieldwork. Taking a reflexive tone, I have shown that the processes of seeking ethical approval from SCREC as well as attempting to gain access to a local authority site shaped my fieldwork practices. As a result of the ethical approval process I imagined that I would be conducting research in a discrete social work team; however, on contact with Kotoka, I realised that my research site would be an integrated team. Because Kotoka was a multi-disciplinary team, I could involve different professionals besides social workers in my research. As such I interviewed and observed more professionals than initially envisaged. I also collected multiple documents from different sources. Similarly, while prior to starting fieldwork I anticipated involving six service users in my research, in the event access was difficult. However, Abrax, the one service user I gained access to opened up new avenues in respect of the substantive concerns of my research. Thus I modified my broad ethnographic approach to include a case study of Abrax. As a final note to this chapter, I wish to highlight that my fieldwork experiences provide a powerful case for the methodological utility of ethnography in a relatively new field such as studying the MCA. Because there are comparatively few studies about the MCA there was the need for flexibility during fieldwork in order for me to develop lines of enquiry. By conducting ethnographic research, I was able me to modify my fieldwork practices while adhering to my methodological and epistemological stances. Since I started fieldwork without pre-defined research questions and aims (as encouraged by some ethnographic writers (Fetterman, 1998; Amit-Talia 2000; Fox, 2004)), I could orientate the substantive concerns of my research. In the next chapter, I therefore

discuss my observations in Kotoka, namely; how the MCA is operationalised within an integrated service.

CHAPTER FIVE. INTEGRATED ADULT LEARNING DISABILITY SERVICES AND THE MCA

Focusing on ethnicity and learning disability, this chapter addresses my research question on how integrated adult learning disability services are discharging their statutory duties under the Mental Capacity Act 2005 (MCA). Firstly, I present findings on the internal workings of Kotoka, an integrated learning disability service where I conducted fieldwork. Given that the core participants of my fieldwork were social workers, I highlight the social work team, contextualising it within the broader integrated service.

The literature review also highlighted the paucity of empirical studies on the operationalisation of the MCA. More specifically, the literature review showed a knowledge gap in how integrated learning disability teams approached their statutory duty to assess mental capacity; and relatedly, how social work contributed to this quest. In seeking to provide some evidence from fieldwork, the second aim of this chapter contributes to research and knowledge of the MCA as an emerging substantive field of enquiry.

This chapter is in three parts. In Part One, I present data on the internal workings of Kotoka. In Part Two, I build on the ideas from Part One to illustrate how informal practices permeated the assessment of mental capacity. Finally, in Part Three, I illustrate how professionals drew on the MCA when they investigated allegations of abuse or drew up protective measures. In Chapter One, where I discussed my epistemological positions, I argued that social constructionists draw attention to context as a significant determinant of meaning generation: in making

sense of the world people draw on material, human, and temporal resources. Through this chapter, I demonstrate that notwithstanding the increasing bureaucratisation of services, institutional contexts influence how the MCA is implemented; context can circumscribe or engender professional discretion in relation to statutory obligations. Part One below, picks up the discussion about context, and I show how teams are configured within my fieldwork site.

Part One. Scene-setting: services' integration and eligibility in Kotoka

The integrated service, Kotoka, is an amalgamation of social care and health services. While there were no eligibility criteria for health services, statutory social care was allocated according to the Fair Access to Care Services (FACS) guidance (DOH, 2003; 2010) under which one had to be assessed as either of 'critical' or 'substantial' need to receive services. To become a 'service user' or 'case', one had to be referred through a completed Referral Form and be classified as learning disabled. Notionally a transparent policy in Kotoka existed for processing new referrals. There was a multi-disciplinary Referral and Intake Committee (RIC), involving managers of the sub-teams, which met on Tuesdays to discuss new referrals. At RIC, decisions were made as to which sub-team would conduct the needs assessment. Once assessed as eligible for a service, for administrative purposes, the referral acquired the status of 'a case' and would be allocated to one team or professional after the RIC meeting, and this in turn influenced categorisation. For instance, if the new case was assigned to the social work team, then the category would be social care. In the social work team, one

was initially classified as an ‘unallocated case’ until assigned to a social worker’s caseload, at which point a service user acquired the status of ‘a case’.

Due to tightening eligibility criteria most allocated cases were ‘complex’ and stayed ‘open’ for a long time. Professionals become acquainted with the case even if not the details; thus walking around the social work team, I heard service users referred to by their names instead of as a ‘case.’ In practice, different professionals were simultaneously assigned tasks on the case and the category of individual cases changed with time. For example, an individual might be discharged from section in hospital (the 1983 Mental Health Act’s powers of detention) and become subjected to a Supervised Community Treatment Order (CTO)¹⁴. Although this would primarily be a mental health issue, in Kotoka, a social worker would also be involved to address the person’s social care needs such as welfare benefits, accommodation, food, or clothing. Along the line, the service user might need accommodation, and this would lead to the involvement of an Occupational Therapist (OT), if adaptations were required to the new residence. In Kotoka, professionals believed that being part of the same ‘integrated’ service led to better service provision because the three professionals in this described scenario - psychiatrist, social worker, OT – would easily agree on how the case should be managed. This sharing of roles was called ‘joint working’ and some professionals believed that collaboration with colleagues from different disciplines was one of the merits of integration.

Having set the scene for this chapter by describing how one acquired the status of a case, and having also introduced the concept of joint working, I now explore how these were manifested on the ground in fieldwork.

¹⁴ Under new legislation in 2008 a CTO is an alternative to hospital detention and the service user is treated in the community by a psychiatrist.

The impact of service integration

I start this section by presenting data on two opinions on the benefits of integration from the viewpoint of two professionals: one a social worker and the other a Person-centred Planning (PCP) Coordinator. Extract 1 contains the views of social worker Adwoa, which I recorded in field notes after shadowing her. In this extract, she suggests that being part of the same service, in the same location enables joint-working. Extract 2 was obtained from a taped interview with the PCP Coordinator who described his role to me as akin to an advocate for service users: ‘about the inclusion to ensure that the people we support are being consulted and involved in the process and that includes the process of driving policy’.

Extract 1. Integration makes work easier; makes joint assessments easier; working relationships better; but feels that they could interact better (Field note, Adwoa, 7 June 2011).

Extract 2. I’m a huge fan of it and it is the way to go, it’s clearly the way to working because in a sense it is a Person-Centred way to look at it because if you’re within [...] I mean if you’re accessing a service, and you can say this when I do training for family groups, it doesn’t matter who you call if it’s in this office, if you need to get hold of a nurse, and they’re not around, if you happen to have my number, phone up, call me and the chances are I can see who you want and I can signpost you very, very quickly. It often happens that way. I’ll be sat here and somebody can just ring, dialled the number they happen to have and actually find the solution within minutes whilst they’re still on the phone. You know from a

customer experience people really appreciate that. (Taped interview, PCP Coordinator, 28 July 2011).

The PCP Coordinator and Adwoa's views were contrasting pictures about integration, primarily because of their divergent roles in the organisation. Adwoa (a social worker) focused solely on the internal workings of Kotoka, drawing attention to how being part of the same team enabled professionals to conduct joint assessments, and how integration also fostered better working relationships between professionals. By contrast, the PCP Coordinator emphasised the service user experience. The two pieces of data I have presented above show how even in the face of integration, professionals held divergent views on the merits of uniting different professionals within one organisational structure. These individual accounts may also be due to distinct professional identities.

Being a social worker, Adwoa was central to the work of the service because she had to coordinate the work of other professionals, hence her wish that professionals' interacted more closely. On the other hand, the PCP Coordinator saw himself as an advocate for service users; consequently, he was happy that any professional within the integrated team could serve as a point of contact for service users, as per the picture presented to the outside world that Kotoka was a unitary service. Thus although Kotoka's publicity material presented images of a unitary organisation, with familiarisation, I uncovered specialist teams with relative autonomy to set their own internal policies and preference to maintain their identities. It is perhaps for this reason that Adwoa expressed her wish that the teams 'could interact better'.

During fieldwork most professionals identified spatial proximity between professionals as the key advantage of integrated services with little mentioned about procedural commonalities. A consequence of being in close proximity is that informal work practices were encouraged which helped to manage the complexity of the cases referred to the team. One way by which professionals learnt to manage complicated cases was by negotiating the trajectory of cases outside any formal organisational procedures. Professionals from various teams walked to each other's desks, discussed the case and agreed on what to do, without necessarily referring to their team managers. Because these discussions were informal, one rarely noticed professionals document the agreements reached. Managers, on the other hand, relied on these informal negotiations of case trajectories to bypass professionals of lower rank in other teams who refused to accede to requests. This was explained by Jo, a female senior OT manager, below in a taped interview:

Well I suppose those meetings [RIC] are really just where the paperwork comes or discussions happen to make sure that the work between professionals is recorded. I suppose it is rubber stamping but I would say a lot of that happens because we're able to discuss, you know, people [service users or cases] you know. If I have got a difficult case I would probably go to the duty at the social work team - 'not sure about this can I bend your ear? You know, is there any possibility of something happening?' Perhaps this is a social work sort of issue that they can help us out in OT and I think we do a lot of that. Because we know each other and I think the rubber stamping of that will then happen in RIC (Taped interview, Jo, 4 August 2011).

The quote above was in response to my question about how cases were allocated within Kotoka. Jo explained that usually if she (or more accurately her workers) needed help with social work tasks, she requested help directly from the social work team. In the process, Jo subverted formal procedures stipulating the completion of referral forms. To directly seek help from the social work team, Jo constructed or drew the conceptual boundaries of 'a social work sort of issue'. Moreover her subordinates in the OT Team may not have been present at the discussion with the social work team and although they may be informed of the outcome, they were deprived of the detail of the negotiation. This situation would be mirrored on the social work team which informally accepted the request for help. Informal negotiations in Kotoka sped work up but perhaps to the detriment of workers keeping track of details of cases.

An equally important point to note from the OT manager's quote above is that when presented to RIC where it is formally recorded, professionals at the meeting are in effect agreeing to decisions made in their absence. Resulting from the 'rubber stamping' role of RIC, in Kotoka, professionals could not assume full responsibility for their allocated cases since other key decisions were sometimes made by professionals in other teams. Furthermore, the extensive use of informal discussions in Kotoka, coupled with assigning multiple professionals to a case meant that professionals were not always up to date with developments on the case.

I now present some data from my field observations to demonstrate how, even within the same team, information about a service user could be fragmented, with implications for assessments. The three central characters in the data were all social workers: Mavis, Annika, and Claire. I recorded the data extract whilst shadowing

Mavis, when she recounted a mental capacity assessment she conducted. Annika who was sitting next to me interjected and told me that ‘this is an interesting case to follow’. Then Claire, occupying the opposite desk, joined the discussion because she had just been allocated the case. As such, all three social workers had been involved in the case at different key points of the service user’s life. Mavis was asked to work with the service user when he was evicted from his placement because he injured a professional. Annika’s role was to conduct an annual review. Subsequently Claire became involved as the newly allocated social worker.

Annika said that at the annual review the main issue was that the service user wanted to move to Japan to meet a woman that he had formed a friendship with on a social networking site. In Annika’s view the service user’s father was not helping the situation because he promised to go to Japan with him even though he displayed very little commitment to his son’s care. Annika said that at the annual review her analysis was that the service user has a character for ‘fixations’ and as much as she tried to move the conversation on to a consideration of the consequences of going to Japan, the service user would not deviate from his insistence on wanting to go to Japan. Mavis said that she had not heard about the service user’s desire to go to Japan – ‘this is the first time I have heard of it’. (Field note, 30 June 2011).

The MCA Code of Practice suggests that assessments should be conducted by people who know the person well; but in the data extract above, the social workers had access to discrete pieces of information about the person. Crucially, in the case of

Mavis, when she conducted the mental capacity assessment, she did not know that the service user had once said that he wanted to move to Japan. Thus, whereas the policy drive towards statutory service integration is underpinned by the assumption that communication between professionals would improve care (Petch, 2011), in Kotoka, there was fragmentation of information. While nearly all professionals in the study agreed that spatial proximity made it easier to discuss cases, on the other side, information was dispersed over a wide network of professionals, with no one accorded ultimate responsibility for building a holistic picture of the service user. That social workers amass discrete pieces of information without forming an analytic thread has long been recognised (Wilkins and Boahen, 2013); however, in the integrated services literature, it is taken for granted that unitary organisational structures would improve professionals' share of information. The data presented here involving Mavis, Annika, and Claire challenges the supposition of better information sharing.

Another important finding from Kotoka challenged the assumption in the integrated services literature that amalgamating separate professions into one service led to unhealthy competition (Maslin-Prothero and Bennion, 2010). There were blurred professional boundaries because professionals (or teams) shared tasks. However I did not record any instances of professionals in competition for roles or to take the lead in case management. Whereas it has been long recognised that the boundaries of 'social care' or 'social work' are difficult to define (Shaw, 2012), arguably health workers have a stronger sense of professional identity because of their relative specialisms. Thus teams identifying as 'health' could name their specialities and as such in Kotoka, they could clearly establish the tasks that they were competent to carry out and vice versa. On the other hand, in Kotoka, social workers were

involved in nearly all 'complex' cases; in all the multi-disciplinary meetings that I observed, I noticed the presence of social workers, and the social work team seemed the starting point for case allocations. In the next section I present data to explain that one reason for the apparent lack of professional competition is because social work was accorded centrality in Kotoka.

The centrality of social work in Kotoka

In an environment of fragmented information, blurred professional boundaries, and informal working practices, the social work team was accorded an omnipresent status and a unifying role within Kotoka. Although relatively small in number, social workers played a central role in the organisation of work in Kotoka. In the next section, I briefly describe the structure of the team before discussing the role of the team from the viewpoint of the social workers and other professionals within Kotoka and the local authority.

Gender and spatial constitution of the social work team

The social work team changed significantly in the course of fieldwork. The core participants of my research, who I have described in the methods section (Chapter Four) remained in post; however, one social worker, Ofira, who I had shadowed for a few weeks left and was replaced by two female social workers and a Care Coordinator. Furthermore the team was augmented by two Reviewing Officers. In the lower ranks of the team, females were numerically dominant but, arguably, no one ethnic group had a higher share of the workforce; additionally, there were more qualified than unqualified workers. The management structure of the social work team consisted of three female assistant managers and one male white service manager (Chris). The names of the managers and ethnic identities (assigned by me) were as

follows: Monica (Polish), Sandra (Turkish), Danielle (who I thought of as mixed heritage). Thus the one qualified male social worker in the team was the overall manager; therefore, a white male in the group held power disproportionate to the numerical representation of men.

Ironically the social work team was not spatially integrated because social workers occupied two separate offices split over the ground and first floors. Chris and Danielle shared a big desk in one corner of a large open-plan office on the first floor with other members of the integrated team. Sitting next to Chris and Danielle was the administrator of personalisation. Each sub-team in the service occupied the same space but, because the two social care managers sat in a designated corner of the office, when I was first introduced to the first floor, I felt that they were separated from the rest of the social work team. The feeling of separateness was repeated on the ground floor where four members of the social work team sat together around a desk, including the Duty Social Worker, called 'Duty' by professionals. The spatial division of the social work team affected the types of cases emanating from the ground floor office.

One of the key roles of the Duty desk was to act as a point of contact for 'emergency' cases. Therefore, there was a social worker permanently available 'on duty' to answer telephone calls and unscheduled visits by service users and/or their carers as well as professionals from Kotoka and the wider local authority. In addition to their other duties, social workers were diarised as Duty for a week at a time. In case there was an emergency requiring their absence from the office, each Duty usually had a deputy to take over their role. Sitting next to the Duty desk was Assistant Manager, Monica, who also acted as Duty Manager. Among social workers Monica had a reputation for being knowledgeable in safeguarding issues. Through a

combination of professionals on Duty and Monica's standing as an expert in safeguarding, many 'alerts' originated from the Duty desk. These factors outlined here arguably explain why the OT manager, quoted previously in this chapter, said that she would walk to the Duty desk and ask for help if required.

Social work as omnipresent and moral

In Kotoka only the social workers had a fully computerised workflow processes I call Ebony¹⁵. While using Ebony frustrated social workers because they saw it as too cumbersome, the speedy ability to retrieve information on service users granted social workers power and status through efficiency and made them knowledgeable about service users' life histories. Although access to Ebony increased social workers' power vis-à-vis other professionals, it also increased their workload. During one shadowing session with Audrey, I observed and took notes on her work on the Duty desk. To illustrate the cumbersome nature of Ebony, Audrey told me about a letter she had received that day from a psychiatrist sitting a few yards away from her in the same office. The psychiatrist had written to the social work team to request that a service user's care package be increased. Although Audrey and the psychiatrist were co-located, the letter was first typed by the psychiatrist's secretary, and emailed to Audrey for her to upload on Ebony. Once uploaded, Audrey then had to make another record of the email exchange with the psychiatrist in Ebony. Seemingly a convoluted process, the uploading of information nevertheless placed Audrey at the apex of coordinating the service user's needs.

¹⁵ I have used 'Ebony' as a term of anonymity.

During fieldwork in Kotoka I heard more stories about social workers being involved in a wider range of cases than other professionals. In one sense the apparent omnipresence of social work in Kotoka can be explained in policy terms. The main gateway for disabled adults to access services is through care management assessment, and this has resided within social care teams (Lewis, 1997; Cambridge et al, 2005; Cambridge, 2008; Trevillion, 2007). Furthermore, current policy identifies social work as the ‘lead professional’ in safeguarding investigations (SCIE, 2011). Thus with Kotoka being a learning disability service, arguably it was no surprise that I observed social work given prominence by other professionals. Nevertheless I also observed that social workers were under tremendous pressure due to their high caseloads.

One way in which the social workers managed the stress caused by high caseloads was to ascribe a moral dimension to their work, such as the need to protect or enhance service users’ autonomy, or their right to make decisions for themselves. Thus during shadowing of Mavis, she told me that her practice was influenced by her belief that people had a right to make decisions for themselves:

She said that she believed that people had the right to make decisions for themselves even within the context of parent-child relationship. Mavis spoke passionately and eloquently [about her values] (Field notes, 22 August 2011).

Another form of morality that social workers ascribed to their profession was that they saw it as their role to improve lives. Audrey, who I regularly observed taking

work home over the weekend, maintained that she did not ‘get emotionally involved’ and wished to improve service users’ lives:

Audrey said that she tries not to become emotionally involved. Her view is always that whatever the service user’s life up to the point that she has been allocated the case her job as a social worker is to make their lives better. Once she leaves the office she forgets about her cases - ‘leave work behind’ - but in the office she is fully committed and ‘gets stressed sometimes’. (Field note, shadowing Audrey, 22 July 2011).

Similar to Audrey’s views recorded above, Adwoa also told me on 22 June 2011 when I shadowed her that, even where families had complained about her, she still worked with them to improve their lives. That social workers feel that their role is to make service users’ lives better is widely recognised in the literature (Shier and Graham, 2011). Within Kotoka, however, the moral dimensions of social work identified in this section, arguably, were means by which professionals constructed a unique identity from their other (non-social work) colleagues, or coped with the physical and emotional demands of their roles. Nevertheless the organisational structure of Kotoka sometimes caused tensions between social workers’ claims to ethical practice and the expedient need to deal with high case loads.

Tensions: rights-based practice, team culture and identifying mental capacity issues

To manage high case loads, there was a set of accepted practices that amounted to a culture within the social work team (Kunda, 2002) of assessing new service users in the Meeting Rooms in the office after referral had been processed through RIC.

Another practice was that close family members and carers were encouraged to be present at home visits. Both practices described here saved money and time; unless necessary social workers did not have to travel too often nor did they have to routinely provide accessible information formats for service users. In any event the cases that social workers dealt with were complex or 'juicy' (as explained by Annikka): 'cases that get allocated something need[s] to be happening like someone has to be moving [accommodation], they are more urgent' (Field note, 13 June 2011). Allocated cases involved multiple professionals and several dimensions: for instance there might be housing, medical, or benefit issues which need to be resolved simultaneously. Consequently it was deemed that not all service users could follow the discussions; therefore, it was expedient to make carers and family members the focal points of discussions about service users. Because Kotoka was located in the busy town centre with heavy traffic, service users would require close supervision; therefore, most carers attended alone. Also, as explained to me by the PCP Coordinator during a taped interview, service users eschewed coming to the office because they associated the building spaces with 'crises':

You see a lot of the people we support don't like this building, I mean we think it's a friendly, nice comfortable office, building, but a lot of people have an association with this building of stressful meetings: 'this is where I went, when my placement broke down that's where I went, I went to that reception room, I lost my flat I went to that reception room, mum died'. You know so often people's first access to a team like this will be because there's been a crisis. So the next time there's a crisis, what you do – you

bring them back to the same building. (Taped interview, PCP Coordinator, 28 July 2011).

Apart from association with 'crises' as explained by the data extract above, another downside to conducting assessments within the confines of Kotoka was that professionals missed opportunities to observe service users in different environments in order to understand how they made everyday decisions. In another sense it may be hypothesised that, besides expediency, the culture (or practice) of conducting assessments on the premises of Kotoka and/or making carers the focal point of home visits, served to resolve some moral quandaries for social workers around mental capacity. For, unless in exceptional circumstances, professionals did not have to confront the moral and legal minefield of ascertaining whether service users had mental capacity to understand prevailing 'crises'. Moreover by making carers the focal point of discussions, professionals deferred any ethical dilemmas about whether they shared similar meanings with service users about mental capacity. The practice of bypassing service users also negated any moral requirement to seek consent from them to intervene in their lives. In effect, the culture of assessments allowed the social work team to bypass some of the stipulations of the MCA and some of the moral quandaries about how to obtain consent for interventions.

The hypothesis that I have described above could explain how social workers in Kotoka reconciled the contradictions between the team culture of conducting assessments in the office space, and their belief in the moral quest of their profession to seek service users' consent for interventions. Where professionals processed a new referral they resolved the tension between their moral imperatives and the team's culture by 'casting' another person (usually the carer) into the role of making

decisions on behalf of the service user. Thus it was striking that when social workers discussed care packages with carers they used the word 'you' as if they were arranging services for the carer instead of the service user. For instance on 21 June 2011, I observed a meeting between Ofira and Mrs Pike during which her daughter's care package was reviewed. There were complex discussions around the suitability of the current care package but I noticed that Ofira made Mrs Pike rather than her daughter the focus of the discussion and this led me to make the following observation in my field notes:

6 weeks respite has been agreed – 'so you can use it how you like': This statement struck me because it chimed with my earlier observations about how social workers address carers as 'you' as if the services were for the benefit of carers rather than the service user. (Field notes, 21 June 2011).

The present discussions about the informal culture around how social workers conducted assessments in Kotoka are within the context of my aim in Part One to explore the nature of integrated services in Kotoka. I have shown in Part One that, organisationally, Kotoka was a unified learning disability integrated service and was presented as such to service users. However the internal dynamics of the service was that of several sub-teams using informal practices to meet service users' needs. The model of integration was universally appreciated in Kotoka; nevertheless, each profession provided different reasons for the efficacy of joint-working. Amidst the informality and blurred professional boundaries arising from spatial proximity and professional collaboration, the social work team may be seen as a unifying thread of the organisation. Social workers were involved in most cases because of the fluid

nature of their professional boundaries as well as their role as the gateway to most statutory learning disability services. Part One of this chapter has, therefore, been about the institutional context of my research. Building on the explanations of Part One, in what follows in Part Two, I highlight another surprising finding from my fieldwork in Kotoka; namely, the infrequency of mental capacity assessments. Taking as the point of departure my previous explanation of informality, I start Part Two by discussing how mental capacity was conceptualised.

Part Two. Conceptualising mental capacity in Kotoka

During one shadowing session (on 13 June 2011), I asked Mavis (social worker) about the infrequency of capacity assessments. Her response was ‘We’re not doing capacity assessments everyday but once in a while’. Throughout many weeks of fieldwork in Kotoka, I did not witness or observe a formal mental capacity assessment. In the MCA, learning disability is identified as one of the triggering conditions for capacity assessments so it was reasonable to expect that within Kotoka – a learning disability service - capacity assessments would be routine. Moreover the thrust of current learning disability policy is increasing choice, independence, and empowerment (Hollomotz, 2012), which arguably are underpinned by mental capacity. Consequently, I hypothesised before fieldwork that I would observe several capacity assessments, but this was not to be the case in Kotoka. Here in Part Two, I present data to show that a probable reason for the infrequency of capacity assessments is that professionals, service users, and/or their carers in Kotoka operationalised mental capacity more broadly than defined by the MCA’s legal framework. As such, Part Two builds on my explanation in Part One that the

institutional context of my research was one of blurred professional boundaries, joint working, informal work processes, and fragmented information sharing.

Distinguishing between formal and informal capacity assessment

The definition of mental capacity in the MCA is what I conceptualise as formal capacity assessment. The main distinction between a formal and informal capacity assessment is that the former is documented whereas the latter includes the judgements made about a person's capacity to make decisions outside the MCA framework. In Kotoka, formal capacity assessments are written on a designated form called Capacity Proforma, at which point the assessment is official. The culture within the service was that the professional who knew the service user best assessed their mental capacity:

Mavis suggested that the culture with the Integrated Team is that the professional who knows the service user best conducts the assessment.

(Field notes, 30 June 2011).

In the MCA Code of Practice (2007) it is advised that assessment of capacity should involve people who know the service user best, therefore the culture within Kotoka captured in the above data extract mirrors statutory guidance. However, in their daily interactions, professionals in Kotoka also judged service users' mental capacity without due course to the Capacity Proforma or the MCA.

Jenkins (2000) has argued that (self)categorisation is an indispensable and unavoidable means of making sense of a complex world. By Jenkins' postulation, the

informal assessment of capacity by professionals may be one way that they navigated their myriad duties. Contrasting Jenkins' thesis, in some of the 'caring' services literature, it is argued that documentation 'creates' or 'constructs' the service user according to institutional indicators. Barrett (1996) in an anthropological study of a psychiatric institution – the study involved psychiatrists, social workers, and psychiatric nurses – found that the case notes of patients sometimes differed from the conditions that they presented with. Barrett's explanation of the discrepancy was that the process of documenting needs led to the construction of a patient different from their self-descriptions. Similar arguments to Barrett's have been made in respect of the completion of electronic assessment forms in social work, where it is argued that the layout of forms influenced the assessed needs of service users (Pithouse et al, 2009; White et al, 2008).

However my observations in Kotoka identified practices that may be said to conform more to Jenkins' postulations in that construction of service users' mental capacity temporally preceded documentation. By the time social workers documented their capacity assessments, they had judged the service user's capacity. Informal assessments were conducted on the basis of the social worker's intuition, the service user's presentation, and prior categorisation by other professionals. Moreover, service users in their daily lives articulated and demonstrated capabilities which challenged the MCA's legal framework. Some social workers also believed that all the MCA had done was formalise social workers' value-base to seek people's consent before interventions; and in this sense, the legislation was a bureaucratic nicety.

Informal perceptions of mental capacity

In this section, I discuss how professionals, service users, and/or their families (or carers) conceptualised mental capacity. To do so, I draw on a mixture of first-hand

accounts and my interpretation of data. The section is presented sequentially and thematically thus: mental capacity as communicating, mental capacity as social relations, and PCP and the MCA in Kotoka.

Mental capacity as communicating

In Kotoka, one of the key yardsticks of informal capacity assessment was whether the service user's means of communicating was regarded as 'non-verbal'. By 'non-verbal' professionals usually meant that the service user did not communicate in coherent sentences intelligible to them. Because being 'non-verbal' linked to incapacity, 'verbal' service users were generally considered to have capacity. Professionals taking this view believed that how a service user communicated was a window onto their capacity; if you communicated verbally, then by corollary you were more capable than those who couldn't or didn't. One instance that explains 'mental capacity as communicating' was the case of Mandy, who Audrey, a social worker, was convinced needed to move from a big nursing home to a smaller unit. In preparation for the move, Audrey and I visited Mandy to conduct an audit of her clothes. On our return I asked Audrey whether a mental capacity assessment had been conducted prior to Mandy's move. Audrey's response is revealingly captured in my field notes below:

Audrey told me that in the case of Mandy she had not done an MCA assessment because it was clear that she was 'non-verbal' and did not have any mental capacity to make decisions for herself. Audrey said that she felt that because Mandy did not have mental capacity to decide for herself (about choice of accommodation) she had felt that it was in her

best interest to move to a smaller accommodation with a higher staff-to-service user ratio. (Field note, 20 June 2011).

Typical of informal capacity assessments, Audrey then assumed responsibility to make decisions for Mandy without recourse to a Best Interest Assessment. In so doing Audrey fused stages one and two of the MCA; once she decided informally that Mandy did not have capacity, the next logical step was to 'protect' or 'enhance' Mandy's best interest. In this way, there was the paradoxical situation whereby professionals felt that they were 'protecting' service users' rights although they had denied them the right to a formal capacity assessment under the MCA. Thus, one inference I can make from the data extract above is that, despite not conducting a formal capacity assessment, Audrey felt that her actions were moral because she was protecting Mandy's best interest, which was the need for a smaller nursing home.

Mental capacity as social relations

Another informal conceptualisation of mental capacity was that it could be inferred from a service user's lifestyle juxtaposed with what professionals regarded as the societal norm. Here professionals operated a more expansive conception of mental capacity beyond cognition. Rather than capacity flowing outwards from the person, professionals ascribed mental capacity on the basis of service users' fit into social norms or 'social capacity'. The concept of 'social capacity' was coined by social worker Annika, in a meeting which I observed as part of my shadowing her. During the meeting, the Chair asked Annika whether she had conducted a mental capacity assessment. Annika's response was noted as follows:

Social worker feels that she has capacity [but current capacity] issue is to do with her 'social capacity': Annika was saying here that service user has cognitive capacity to make decisions but lacks the skills to change her social situation. (Field note, 14 June 2011).

In her response to the question about whether she had conducted a capacity assessment, Annika argued that cognitive capacity was not the main concern with the service user. Rather, it was whether the service user was willing to enact changes to her current social situation. Hammersley and Atkinson (2007) suggest that sometimes the concepts ethnographers develop from data analyses emanate from the words that research participants used, so taking their advice, I sought other instances of 'social capacity' as coined by Annika.

'Social capacity': viewing sexual relations as mental (in)capacity

One strand of mental capacity as 'social capacity' linked to sexual behaviour and here, professionals' assessment of service users' mental capacity centred on their moral evaluations about the latter's sexual lives. Because moral pronouncements nested within informal capacity assessments, in many instances, service users' demonstration of capacity was not sufficient grounds for professionals, and service users needed more than mental capacity to be permitted to engage in certain actions. In what follows I introduce two data extracts to illustrate how professionals sometimes evaluated a person's mental capacity through moral prisms.

The first data extract is from a transcript of a taped interview with Emma, a deputy manager of the Safeguarding Team. Emma, who may be said to be operating with a notion of mental capacity as 'social capacity', suggests that questions of money

and sexual relations elicit more concerns from professionals who probe further, even where the service user has informally demonstrated capacity:

And obviously anything that involves service users having sex or giving away money or anything like that, you need to establish ‘does this person have capacity to do that?’ In which case it’s entirely their business and we don’t need to have a safeguarding meeting. But if they don’t then obviously that’s much more serious. (Taped interview, Emma, 1 July 2011).

In the quote above from an interview with Emma she explained that questions about sex and finances provoked even more scrutiny about a person’s decision-making capacity. As such in Kotoka I heard references to folklore cases around the ‘taboo’ subject of sexual relations. Some cases involved the local authority initiating legal proceedings in the Court of Protection to prevent service users being ‘forced’ into ‘arranged marriages’ by their families. In other cases where service users said that they consented to sexual intercourse, professionals still felt that they needed to ‘take action’ to ‘protect’ them.

The data below highlights Kotoka’s approach to the taboo subject of sex. The central character in the data extract is Amber, a woman of Irish-Italian origin in her mid-20s. Amber became known to Kotoka following reports by her family that she had been ‘sold into sex’. In narrating Amber’s case to me, her social worker, Rose, questioned whether she should be classified as learning disabled, given her high cognitive capacity: for instance Amber had paid employment as a children’s nursery nurse, and she was not known to Kotoka until aged 21. Nevertheless once Amber’s

parents reported her apparent sexual profligacy, a six-month Protection Plan was devised for her whereby professionals from a private care agency escorted her on public transport ostensibly to 'keep her safe'. After six months, Amber was adjudged knowledgeable enough to take the buses on her own. Subsequently, alone on the bus, she was telephoned by sister's boyfriend inviting her to his flat. The data extract below picks up the story:

When Amber went to the flat she had sex with her sister's boyfriend. All this came to light because Amber told one of the workers in the supported accommodation. Despite telling the workers that it was consensual, she was 'examined' by a doctor who apparently found some marks on her thigh and from that it was concluded that 'something had happened' and according to Rose [social worker] the marks on Amber's thigh suggests that 'it was rough sex'. I gathered from Rose that the learning disability team's main concern is that Amber is at risk from sexual exploitation stemming from the previous reports from her family and the supported accommodation. Interestingly Rose appeared to believe that Amber understands what is entailed in sexual intercourse and Rose also believed that Amber has the capacity to consent. However Rose also believed that Amber did not understand the emotional consequences of the consenting to sex. I said to Rose that I was raising the possibility, as a thought experiment, that Amber would say she was well aware of the risks, nevertheless, she still wanted to have sexual encounters. Rose said that were this to happen 'then we will have a big meeting with everyone to decide whether she can understand [to consent to profligate sexual

encounters]’ and Rose added that a Best Interest assessment would be conducted (Field note, 13 July 2011).

In the last sentence of the paragraph, Rose confirmed that capacity to consent was not the sole requirement for learning disability service users to engage in sexual relations. If Amber chose to have multiple sexual relations then a ‘big’ meeting would be held for professionals to decide whether Amber understood the ‘emotional consequences’ of a life of sexual profligacy.

Contextualised within the MCA and service provision in Kotoka, Amber’s case illustrates that around sexual relations, professionals and some families do not equate a cognitive ability to make decisions on a par with the right to lead a chosen lifestyle. Furthermore, the two cited data extracts in this section suggest that sexual relations and financial matters circumvent the ‘unwise decision’ principle of the MCA: professionals cannot allow ‘unwise’ decisions around sexual morality and money, and this is especially so if a service user’s family agrees with officials’ stance. Finally, the involvement of Amber’s family in her first encounter with Kotoka shows that where interests converge, some families form an alliance with professionals as guardians of morality. Families play vital roles in the conceptualisation, acknowledgement (or denial), and guarding of service users’ rights to certain lifestyles.

Social relations: families, Kotoka, and service users’ mental capacity

In Kotoka, when professionals referred to ‘the family’, they often meant a biological relation, usually parents. During fieldwork I observed ‘caring’ as overwhelmingly genderised: usually professionals identified mothers or sisters as carers (most of the service users I observed were accompanied by their mothers), while fathers were

considered to be income earners. Because mothers ‘cared’ they knew the service user well and could tell professionals their capabilities. Where mothers acted as sources of knowledge about the service user, they were a useful resource that professionals could draw upon; thereby negating the need for a formal capacity assessment. Thus, because the family ‘knows the person best’, a formal capacity assessment was not always necessary, and the family could be cast into the role of providing proxy consent. At the same time, some families in Kotoka (especially ethnic minority families) were considered by professionals to be a threat to service users because they could usurp their right to make their own decisions and ‘force’ them into taboo areas such as ‘arranged marriage’ or sexual relations as is discussed below.

Families: threatening service users

As I have shown previously, professionals and families sometimes agreed that the MCA’s principle of ‘unwise decision’ could be circumvented around sexual morality. At other times, however, families and professionals disagreed on what is meant by ‘social capacity’ leading professionals to label families as a threat to service users’ capacity. These disagreements coalesced around ‘taboo’ subjects such as sexual relations mostly involving South-East Asian families who professionals believed wanted to ‘force’ service users into ‘arranged marriages’. Therefore, the sub-category of the family as a threat intersected with ethnicity and risk (of which there is a fuller discussion in subsequent chapters).

One way that professionals in Kotoka neutralised the family as a perceived threat was by the use of the formal powers of the MCA. Within Kotoka some professionals believed that mental capacity was indeterminable and, as such, it was incumbent on professionals to operationalise the legislation to protect service users. Thus, rather than viewing disagreements with the family merely as different opinions,

professionals resorted to the MCA to ‘warn’ families not to threaten service users’ autonomy. In my conversations with social workers I learnt that one way of ‘warning’ was through issuing a letter from the local authority’s legal department.

The case of Ibrahim, a South Asian man who became known to the service because of concerns of him being ‘forced’ into an arranged marriage sums up the discussion up to this point. It illustrates how professionals informally assess mental capacity, how families take a holistic view of the service user and, therefore, see them as more capable than professionals do (Edwardraj et al, 2010; Rao, 2006); and how professionals resort to the MCA where they see the family as a threat. My discussion about Ibrahim is based on informal interview data from shadowing Mavis, a social worker, which I present in three extracts below. Ibrahim was referred to the Duty Social Worker by a Community Nurse from Kotoka who, on a routine visit to the family home, was told that a marriage was being arranged for him. In the first data extract below, Mavis explains why the Community Nurse made the safeguarding referral:

Mavis said that the reason why the community nurse had raised the safeguarding alert was because it was evident that the service user did not have capacity and that he would not understand an issue such as marriage (Field notes, 11 August 2011).

From Ibrahim’s presentation as learning disabled, the community nurse felt ‘it was evident’ that he could not understand ‘marriage’ with the corollary that the planned marriage would be against his will. Faced with this possibility, Kotoka felt duty-

bound to 'protect' him. The next extract suggests, however, that in contrast to Mavis, Ibrahim's family believed that he understood the concept of marriage:

Mavis said that one of the cultural issues involved was that the family were very open about the fact that they felt that Ibrahim required sexual fulfilment. Mavis said that she challenged the family that these [sexual] urges may not necessarily be fulfilled by Ibrahim being married because although the family felt that he had urges it may be that Ibrahim did not understand what was involved in sexual relations [...] When Mavis said that I asked her whether Ibrahim masturbated and the thinking behind this was that if he did, then that could be taken as a demonstration of his understanding of how to fulfil his sexual urges (in contrast to Mavis' point). Mavis thought that the nurse 'was doing some work with him [on the issue]' which to me was a confirmation that she was implying that the service user masturbated (Field notes, 11 August 2011).

In this second data extract, Mavis informs me that Ibrahim's family believe that he has the mental capacity to understand sexual pleasure. Of interest, however, is the response of professionals to the family's quest to help Ibrahim fulfil his sexual urges through marriage. Firstly, Ibrahim's sexual urges are pathologised as requiring medical intervention – that of a nurse. Secondly, Kotoka organised a meeting with the family at which they informed them that any attempt to travel with Ibrahim to meet a future bride would be legally contested by the local authority:

Mavis was told by the legal team to inform the family that if they attempted to take Ibrahim out of the country then Kotoka would launch

legal action. Mavis said that she was keen to avoid legal action and tried to be 'flexible' in her work with the family, to accommodate and understand their point of view. Mavis repeatedly said that one of the hallmarks of working with this family is that they have been 'open' and have not resisted professionals working with them. Mavis said that had this not been the case the matter about 'forced marriage' might have ended up in the courts, which as the social worker she did not want to happen. (Field notes, 11 August 2011).

The three data extracts presented in this section illustrate the ambiguous practical, moral, and legal space that families inhabited in the link between Kotoka, service users, and the MCA. It could be argued that families were resources used by professionals in the discharge of their duties to service users. In Ibrahim's case, Mavis said that his family had resisted statutory services for a long time because his mother and sister cared for him. Yet in the taboo subject of sexual relations and marriage, professionals claimed superior knowledge about Ibrahim's needs and felt it the moral duty of Kotoka to 'protect' him from being 'forced' into marriage by his family, who were relied upon to care for him in the first place. There are also hints in the data extract that the family ascribed more understanding to Ibrahim about sexual relations than professionals: for instance in the second data extract above I recorded Mavis as saying that Ibrahim's family believed he had 'sexual urges' but she 'challenged' their views. In previous conversations Mavis had told me that she thought of herself as a defender of service users' rights; however, her position in the case of Ibrahim was to see the family as a threat to his wellbeing. It is also notable that what started off the 'alert' was an informal assessment by a community nurse that Ibrahim was not

capable of understanding marriage; an assessment formed on the basis of how he presented as learning disabled.

The data I have presented up to this point arguably supports a proposition that mental capacity was not the sole yardstick by which professionals and families judged the efficacy of service users' actions. Whereas the MCA advises that formal capacity assessments be decontextualized from values (Dunn et al, 2007), in Kotoka where actions did not conform to the societal norm, this could be taken as evidence of incapacity even though a formal capacity assessment had not been conducted. Aside from viewing mental capacity differently from the conceptualisation employed in the MCA, professionals in Kotoka at the time of fieldwork practised in a policy context described as 'something of a self-proclaimed 'revolution'' (Duffy et al, 2010; p1). The MCA was therefore one amongst a number of policies within the toolkit for practice. One other important policy for practice was Person-Centred Planning (PCP), which in policy terms overlaps with mental capacity (DOH, 2009; Fulton et al, 2008), and could therefore diminish the number of MCA-related assessments.

Person-centred planning and the MCA

Given the link between the MCA and PCP I interviewed the PCP Coordinator about his role. Following the interview, I analysed documents that the Coordinator gave me to read, together with some internal local authority reports available on the Internet. These data painted a picture of the PCP as a policy imperative in the local authority because its widespread use led to the Council being given a nationally-recognised award for excellence called Beacon Status. Furthermore the cases that the PCP Coordinator discussed in our tape recorded interview were all akin to capacity assessments.

According to the Coordinator, in some instances in Kotoka where decisions had to be elicited from service users, their mental capacity was not assessed. Rather, a referral would be made to the PCP Coordinator for him to facilitate the service users' decision-making. However the Coordinator articulated a discourse of choice, rather than mental capacity assessment. The Coordinator gave an account of work with a service user with a persistent violent behaviour notwithstanding several interventions. The PCP Coordinator was thus asked to do some work with the service user to mitigate the violent behaviour. Through close observation, he was able to identify the trigger points for the violence, such as when things were out of place: for example, if a DVD or magazine fell off the table suddenly, or the service user's routines changed unexpectedly. The PCP Coordinator's conclusion was that the service user was demonstrating mental capacity through her behaviour:

That demonstrates that person's capacity in that situation, so they are using their behaviour as their communication; they have the capacity to make a decision, they are communicating something. It is not a behavioural phenotype, it is not a random internal process; it is a rational reaction to a specific environment. (Taped interview, PCP Coordinator, 28 July 2011).

In the quote above, the Coordinator articulated a conceptualisation of mental capacity as communicating through behaviour. Another revealing point about the data extract above is that even though the Coordinator described his work with the service user in terms of mental capacity, at no point did he refer to an assessment under the MCA. During the interview, as the PCP Coordinator described his conduct of PCPs and the

overlap with capacity assessments, I explicitly asked him for the distinction between the two policy strands. I reproduce extract of our exchanges below:

Godfred: So a good Person-centred Plan is in effect a good capacity assessment?

Coordinator: Actually, look, I've not put them in quite those terms before, but yes, I will give you a few more [examples ...] this is just a part of it 'cos the decision-making came so early into Person-centred Planning, the two sort of strands go in parallel and they are very, very consistent [...]

To elaborate further, the Coordinator recounted a case in which he had been asked to facilitate decision-making as part of a care plan review for Blake (a service user). The Coordinator believed that Blake could make decisions based on the fact that, in the day centre, he 'shared' decision-making with others around food for lunch. However, Blake's relatives did not believe he displayed mental capacity in the day centre. Using Person-centred Planning tools, the Coordinator showed Blake's capacity:

It [PCP] allows you to create that spectrum of choice often in a day-to-day thing [...] so you have; it does link into capacity in that it gives you very situation-specific often quite time-specific situation [...] but actually it is about increasing capacity too 'cos it's the choice, it's the skill of decision-making [...] by creating, making choices very easy, finding the choices that are well within the person's capacity, capacity increases. 'You say you are going to have toast or cereal for breakfast' there is a pressure that comes with it so by creating, making choices very easy, finding the

choices that are well within the person's capacity, capacity increases.

(Taped interview, PCP Coordinator, 28 July 2011)

It is noteworthy that in the above data extract the Coordinator paraphrased the MCA's 'decision-specific' and 'time-specific' principles, thereby showing his familiarity with the legislation. Additionally, he demonstrated his conceptual grasp of mental capacity by noting that it could increase (in the MCA, it is noted that capacity 'fluctuates'). However the Coordinator couched his explanation within PCPs and choice, rather than the MCA assessments, even though in essence the two strands of policy overlap. The use of PCPs was prevalent in Kotoka, and their overlap with mental capacity assessments may explain why professionals in Kotoka told me that mental capacity assessments were rare. Furthermore an internal Council document attributed the achievement of Beacon Status to use of PCPs:

Shared good practice with other organisations through the Beacon Status for the Council's work on promoting independence for disabled adults; continued to be an exemplar in the area of [PCP]. (Review of Learning Disabilities Section 75 Agreement, 2010; p5).

The PCP Coordinator's role also exemplified the informalisation of work in Kotoka. Although the Council trumpeted the widespread use of PCPs there were no referral procedures for the service; according to the Coordinator: 'There is no referral process, they [professionals] just have my number'. Arriving in Kotoka on my first day for fieldwork, the Coordinator was one of the first professionals I was introduced to. I noticed that, unlike other professionals, he was not part of a sub-team, an observation

he later confirmed in our interview. As such, the Coordinator enjoyed wide autonomy to determine his responsibilities and roles.

As a conclusion to Part Two, I wish to summarise the discussion up to this point. A counter-intuitive finding from my fieldwork was that in Kotoka, a learning disability service, mental capacity assessments were infrequent. Although, notionally, there was one integrated service, Kotoka was made up of different professions who had their own policy imperatives and identities. Thus there was no one professional who considered it their primary obligation to initiate formal mental capacity assessments. As shown in the preceding discussion, some policies such as PCP which overlapped with the MCA were drawn upon instead of the MCA legal framework. In any case, professionals articulated an understanding of mental capacity beyond the conceptualisation envisaged in the MCA. Such informal capacity assessments employed in Kotoka included ‘mental capacity as communicating’ and ‘social capacity’. I have also shown that certain ‘taboo’ subjects were deemed by families and service users to be beyond the sole realm of mental capacity, and even where service users displayed mental capacity, as in the case of Amber, moral evaluations were employed by professionals. The discussions to date highlight the relevance of social constructionist ideas to the on-going deliberations about the MCA: I have demonstrated that professionals re-interpreted the MCA’s conceptualisation of mental capacity in accordance with their own subjective viewpoints. Consequently, it may be argued that mental capacity exemplifies other ‘social phenomena [...] whose existence and qualities are dependent in a large part on people’s meaning-making practices.’ (Harris, 2008; p233). Having explained the infrequency of formal mental capacity assessments in Kotoka, I now identify the situations that led professionals to draw upon the MCA legal framework.

Part Three. Operationalising the MCA

Here in Part Three, I examine professional practice that accompanied formal capacity assessments by describing two institutional spaces that I was granted access to observe, namely the Safeguarding Team (ST) and the Complex Cases Panel (CCP). The ST advised all professionals in adult services on safeguarding policy whereas CCP was specific to the integrated learning disability service (Kotoka). CCP was a fortnightly multi-disciplinary meeting chaired by Max, the Head of Service. During CCP meetings, professionals were encouraged to discuss difficult cases with colleagues. In this regard CCP was meant to be a form of peer-supervision and thus epitomised a key benefit of service integration, which is predicated on the supposition that pooling together expertise leads to better outcomes (Wistow, 2012). In Kotoka there was a close association between CCP and ST because most of the cases presented at CCP meetings were classified as ‘safeguarding’, on which the latter provided advice and training. I start this section by discussing the contribution of ST to formal capacity assessment.

Mental capacity as indeterminable: the MCA and safeguarding

Policy-wise, safeguarding and adult protection are attaining credence in the UK: ‘safeguarding and adult protection are connected but essentially different; with one relating to the prevention of abuse and the other relating to intervention once abuse has occurred’ (Law Commission, 2011; p19). Reflecting the evolving national policy context, in Kotoka safeguarding also featured prominently in my fieldwork. The Assistant Manager, Emma, when I interviewed her explained the role of the ST as:

‘very much a strategic team is how we refer to ourselves rather than a frontline team. So we’re very much involved in giving advice and we chair some safeguarding meetings’. Staff from the ST chaired safeguarding meetings in the local authority, and also acted as the point of call for advice on ‘safeguarding alerts.’ Additionally, staff from the ST wrote policy documents on conducting safeguarding investigations including: the timing of meetings, topics to discuss, and when mental capacity assessments should be conducted as part of the inquiry. Consequently, the central policy and practice role played by staff from the ST on safeguarding and the MCA meant that their conceptualisation of mental capacity was likely to be influential in the local authority.

Within the ST, a view was articulated that mental capacity was indeterminable; therefore, an instrumental approach had to be taken towards the MCA. According to this view, the MCA should be conceived of as one of the options within a professional’s toolkit to resolve cases. Thus ‘mental capacity as indeterminable’ was underscored by pragmatism and entailed professionals drawing on the MCA powers in casework. Below, I reproduce segments of a taped-interview with Abby (manager of the ST) in which she discussed her view that mental capacity was a complex concept to operationalise:

I think they [professionals] find it [capacity assessments] hard... The law doesn’t specifically say when capacity assessments should be done. I think the guidance is there, the guidance is helpful but I think many practitioners think that it is something extra to do and people rely very heavily, I find, on the first principle of the Act that says ‘presume capacity.’ [Long pause]. And I always say to people ‘behold the first

hurdle' and that is presume capacity because that is a very high and tall hurdle...my view is that if somebody else is asking for a capacity assessment or like sometime you will have family raising concerns, if you have somebody raising a concern, I will always say to practitioners 'do a mental capacity assessment and record it, then you've safeguarded yourself and safeguarded the service user; so that you know if somebody comes to ask you questions, at least you can point to that point in time when you've completed a capacity assessment'. But I think practitioners find it a minefield, it is a really, really complex area of work and I think that especially if you are a newly qualified member of staff, I think that it's, it's difficult.' (Taped interview, Abby, 12 July 2011).

The quote above by Abby captured neatly the view of capacity as indeterminable. Abby explained that capacity assessments were complex endeavours and statutory guidance provided few pointers as to the timing of assessments. As such, Abby advised that assessments should be avoided wherever possible - 'presume capacity because that is a very high and tall hurdle'. However if doubt arose about a service user's mental capacity, a professional should bear in mind that their decisions could face outside scrutiny so they should keep an audit trail of decisions about mental capacity. In the data extract above, Abby is here expressing the view that a formal capacity assessment accords to the debated bureaucratisation of social services (Evans, 2010).

Whereas the ST was an independent team, CCP, which I discuss next, was a multidisciplinary panel and as such, different conceptualisations of mental capacity were manifested. In CCP, gender, ethnicity, organisational hierarchy, and power

intertwined to determine whether a formal capacity assessment was initiated within Kotoka.

Complex Cases Panel (CCP)

During fieldwork, I observed CCP on two occasions (12 and 26 July 2011) and took field notes. I also analysed documents minutes of previous CCP meetings. CCP was called ‘complex’ by professionals and was described positively to me as epitomising the benefits of services’ integration, a forum for peer support, and an avenue for solving intractable cases. Reflecting work processes in Kotoka, there seemed no formal procedure for a case being brought to Complex. All that was required was an agreement between professionals working on the case and/or their manager that a case should be presented to CCP. Once decided, the female administrator of CCP was informed and the case was timetabled. Max usually occupied the apex of an oval-shaped table during CCP meetings. The space he occupied meant that professionals at the table faced him and he could see everyone without being seen by all of them. Professionals from the same team tended to sit together; therefore, rather than being a forum for professionals from different teams mixing, CCP reinforced the feeling of distinct and separate professional identities.

The data extract below, from my field notes of the 26 July CCP meeting, is about a service user, Malcolm, who has worn his shoes for so long without taking them off that they have become stuck to his feet, leading to the possibility of their amputation. The case in the extract was presented by Mavis (social worker). Professionals’ deliberations revolved around Malcolm’s mental capacity to decide to wear his shoes balanced against the risk of amputation. In the extract, SU and SW refer respectively to service user and social worker. I counted 15 females (including both Assistant Social Work Team Managers) and 3 males – Max, Alex (Acting Head

of Psychology), and David (psychiatrist). The gender of the professionals present make it more striking that, in the data extract below, I have recorded only two contributions from female professionals, including Mavis.

1. Malcolm (Duty Case) and Mavis presenting.
2. Professionals meeting yesterday [at which Malcolm was discussed].
Lives at 104. Not engaging with staff [at the unit]. Scared of what he was told. Bad feet in danger of losing feet. Finance (does not want support). Would rather buy DVDs. Mavis -‘He is a hoarder; how do we get him to engage?’ SW [Mavis] thinks [that he] need[s] capacity assessment.
3. Psychiatrist – These issues are historical.
4. Max – Clear there are significant risks. ‘[Max asks] anyone knows him?’
5. He [SU] sits on the fountain by Nando’s. ‘He is independent person. He gets himself out.’
6. Relationship with support workers poor – won’t let them in. Not changing his clothes, has sores on his feet, won’t change socks and shoes. Not known to nursing, social care.
7. Psychiatrist – On-going for six years. The psychiatrist was saying that these issues are not new and that the service user drops on and off of the radar. He seemed not be considering the issues as urgent as Mavis was implying.
8. Not eating properly. Flat needs a ‘blitz’ (clean up) housing wanting to evict him due to uncleanliness.

9. Max – ‘Clearly there may be issues of capacity but clearly we have gone overboard [with concerns about his freedom to choose]’. Max made it clear that he felt that professionals should have seen the seriousness of the issue earlier. He felt that notwithstanding the person’s [mental] capacity professionals should not have allowed his health and living conditions to deteriorate to the point where he might require an amputation.
10. Alex – What has been done before? [Someone responded that] OT involved before.
11. Max – Mental Capacity Act assessment required.
12. Psychiatrist – Communication issue [difficulties] as well
13. [SU] lives with Geoffrey (classified as learning disabled) but independent and volunteers to cook two meals for them
14. Max – Need to explore how Geoffrey can be used [maybe through Direct Payment]. Case needs to be allocated to social worker and Community Nurse. Need to have a plan. Convene Planning Meeting with Treeline [accommodation provider] to know why it has got this far [without the Integrated Team being alerted]. OT to be involved.
15. Query [by another professional about] communication which is relevant to capacity assessment.
16. Max – Speech and Language to be involved [to deal with communication issues relevant to capacity].
17. Alex – If this is a repeated pattern time boundary needs to be drawn
18. Max – [If service user is] dropping out [of engagement with services] then it needs to be picked up at the next Review. Max was continuing

with his theme of being surprised that the service user's condition has been allowed to diminish for so long without professionals noticing.

19. Social Worker [Mavis] – What about capacity assessment?
20. Max – Speech and Language should be at the [Planning] Meeting to help with communication.
21. Alex – Is he [SU] sleeping in his shoes?: Alex wanted to know why the staff in the supported accommodation have not noticed that the service user's shoes are stuck to his feet [...] Alex also wanted to know how service user sleeps on his bed in his shoes.
22. Social worker [Mavis] – Sleeps on couch because [he is] hoarding on [his] bed.
23. Psychiatrist – service user tends to engage now and then, maybe engages with certain individuals. There was a lady sitting opposite the male and next to Max who contributed a lot to the discussion about the service user but I did not have her name.
24. Max – Come back with plan in two weeks. (Field notes, CCP, 26 July 2011).

Mavis started the discussion by highlighting that since the case was brought to her attention, she has escalated it by convening a Professionals' Meeting (point 2). Throughout the discussion about Malcolm, three white male managers contributed and scrutinised Mavis, with noticeable silence from the two female Assistant Social Work Team Managers. Max had to know the intricacies of cases being dealt with because he sat in a large office alone, and was therefore removed from the routine conversations between professionals in the service. Thus, CCP was an avenue for

Max to be informed of the on-going cases in Kotoka instead of being primarily for peer to peer support as indicated to me by the professionals.

Besides acting as a source of information for Max, CCP may be seen as an avenue for him to adjudicate on the tension between professionals' roles: whether to enhance and respect service users' autonomy (mental capacity) or prevent them from engaging in risk. Judging from the last sentence in point 2, Mavis had already decided that Malcolm required a capacity assessment but it wasn't until Max assented to this request (point 11) that other expertise such as speech and language therapy could be mobilised to conduct the assessment. At point 14, Max deployed further expertise, directing joint-working between social worker, community nurse, and occupational therapist. Max also expressed his surprise at the state of Malcolm's feet, admonishing professionals for going 'overboard' with their concerns to guard Malcolm's autonomy and capacity to choose to wear his shoes to the detriment of his feet (point 9). In so doing, Max also pre-judged the outcome of the formal capacity assessment; therefore an intervention would have to occur irrespective of the outcome of the formal capacity assessment.

Since the conversation was dominated by three white males, it is worth analysing their opinions further because their views prevailed. Alex appeared to share Max's frustration at the apparent deterioration of the service user's situation: at point 10 he asked about previous interventions, and in point 17 proposed a strict timetable for intervention, lest the case drifted. The psychiatrist, on the other hand, appeared relatively unconcerned about the 'deterioration' of the service user, noting it was a regular pattern of behaviour with Malcolm. But the psychiatrist also made a key intervention, different from Alex and Max. At point 7, the psychiatrist positioned himself as the one who 'knows the service user best' by reflecting on the fact that

Malcolm's case had been on-going for six years. By putting a time span of six years, he claimed familiarity with the case and, therefore, power to direct its trajectory. As a further elaboration of his knowledge of Malcolm, the psychiatrist is recorded, at point 12, as saying that Malcolm had communication difficulties, which was the salient issue, rather than any questions about capacity. This theorisation would have been accepted as legitimate by the other professionals because he is also a psychiatrist who is formally recognised as an authority to assess capacity in the MCA Code of Practice (2007). Consequently, it is following the psychiatrist's intervention that the discussion agreed the need for a speech and language therapist to be involved in the assessment of capacity, and Max obligingly directed this outcome at points 16 and 20.

The discussion to date shows that CCP was a forum for making decisions to assess a service user's capacity. The discussions about capacity were steered by three males who were white and from a health background. In CCP the ambiguous position of the social work team within Kotoka was also demonstrated. In the minutes of the three CCP meetings, the social work team stood out as involved in the most complex cases: more social workers attended CCP than any other profession and they are allocated the cases on which most contributions are garnered at CCP.

At the same time as they are considered indispensable to achieving good outcomes, the social work team (and managers) appeared to lack the confidence to set a clear pathway for working on capacity-related issues. In point 2 above, for instance, Mavis was certain that a capacity assessment was required; an issue which could have been authorised by one of the social work managers. Yet Mavis also felt the need to have her recommendation rubber-stamped by CCP; it is notable from the data extract above that, although both assistant managers of the social work team were present, neither is recorded as making a significant contribution to Mavis' discussion. Thus,

despite being the lifeblood of Kotoka, social work's distinct contribution to the formalisation of capacity issues remained invisible in the data from CCP, and the observational and interview data.

Finally, it may be concluded from the data extract discussed here that within Kotoka, social workers' moral concerns about autonomy were likely to be subsumed by concerns about minimising risk and 'protection'. This latter point arises from the fact that those with power to make decisions about whether a mental capacity assessment should be conducted, such as Max, take a 'protection' rather than autonomy stance.

Conclusion

Exemplified by the preceding discussions about Complex (CCP), in this chapter, I have presented data on the configuration of services in Kotoka. The data shows that Kotoka consisted of NHS and social care staff, delivering services to people categorised as learning disabled, and whose needs were assessed as 'substantial' or 'critical' (DOH, 2003; 2010). A hallmark of professional conduct in Kotoka was informality, whereby staff decided on the trajectory of cases through routine interactions. Because most NHS staff are 'specialists' and formally diagnose medical conditions, in Kotoka they could specify the contours of their duties. Social work is, however, hard to delineate; as such in Kotoka, social workers drew their professional identities from the moral worth of their roles. Having relatively fluid disciplinary boundaries, social workers were indispensable to the work of Kotoka and were involved in most statutory work, including assessments of mental capacity. I have presented data in this chapter showing that professionals sometimes pre-judged the outcome of a capacity assessment before the formal procedure was initiated. One

reason for informal capacity assessments is that (self)classification is an indispensable aspect of human relations (Zerubavel, 1996). Consequently, instead of being solely an outcome of cognitive activity, that which was identified as mental capacity in Kotoka was the product of human relations.

Humans make judgments about each other's characteristics and behaviour as part of the routine empirical necessity to socialise. Within the domain of statutory services, mental capacity assessments may, therefore, be conceptualised as one instrument among many that professionals and their managers employ to meet their legal duties. In statutory services, notwithstanding the on-going policy drive towards personalisation, risk prevention and/or enablement also remains a pre-occupation of professionals (Taylor, 2005), which is echoed in the data presented about CCP. To the extent that data in this chapter substantiate a social constructionist take on mental capacity, they also highlight the need for examining how the MCA interacts with other embodied categories associated with risk. The next chapter picks up the theme of categorisation to discuss how ethnicity, mental capacity, and learning disability interacted in Kotoka, and the accompanying professional responses.

CHAPTER SIX. SAFEGUARDING: RISK, ETHNICITY, AND THE MCA IN KOTOKA

In this chapter I address my research question ‘the literature review showed that risk is a prime concern of statutory services: how does this relate to the MCA? What understandings of risk are propagated by professionals and service users?’ Contextualised within the MCA’s statutory duties, I analyse data on how risk was articulated and operationalised and in Kotoka, and the institutional mechanisms for doing so. The chapter is divided into two parts: Part One discusses how risk is identified, categorised and managed, and Part Two outlines how people seen as ethnically or culturally different (the Other) were managed by professionals.

Part One. Implementing policy for ‘vulnerable adults’

Within the MCA Code of Practice, incapacitated adults are conceptualised as vulnerable and in need of protection from abuse (MCA Code of Practice, 2007). As such, the MCA links into the policy framework ‘safeguarding’ and accompanying professional practices for ‘protecting’ adult users of social services. As an ‘outsider’ new to Kotoka I was surprised by two issues: (1) how much risk identification and categorisation dominated the routine conversations of professionals and (2) the extent to which ‘safeguarding’ was casually employed by professionals in their descriptions of practice and social situations. The abundance of safeguarding in conversations between professionals on my first day surprised me even with my previous social

work experience in a Disabled Children's Team, during which I participated in many child protection investigations. Stemming from this observation, it was clear to me from the outset of fieldwork that safeguarding would be important to my research; a point I reflected on in my Reflective Diary:

I would need to get a good idea of the workflow of the team pretty soon so that I can focus the research. Talking about [the] focus [of my research] from my first day I can say that safeguarding will also feature prominently in the research. I was really surprised by the number of times safeguarding was discussed within the hour that I sat with Annika, and furthermore during the shadowing of Adwoa. (Reflective Diary, 8 June 2011).

I noticed that professionals used 'risk' and 'safeguarding' interchangeably although I heard 'safeguarding' more often. Safeguarding in Kotoka was used as a noun and a verb: it firstly referred to the type of statutory work carried out to 'protect' service users; and secondly, safeguarding also involved the process of identifying and 'protecting' the service user. 'Risk' on the other hand was used in specific circumstances such as changes in the life course.

Identifying and assessing risk

Risk assessments arose out of exceptional occurrences to service users or around the routine tasks of assessments, care planning, and or reviews. Exceptionally, professionals used the term 'risk' if they meant that service users were in danger at the present time and that intervention was required immediately (Smith, 2010). Reports of immediate danger were received through the Duty Desk. If the service user had an allocated social worker then they would coordinate the organisation's

response, otherwise the report would be dealt with by the Duty Social Worker. Usually when information was received that a service user was at risk, professionals managed events from the office: they either contacted the police or informed others and later visited the service user to (re)assess their social care needs. At other times the police would call Kotoka if, after responding to an emergency call, they felt that the adult in question displayed signs of learning disability. For instance, I was shadowing Duty Social Worker, Audrey, on 2 August 2011 (and taking field notes) when she received a referral in an email that the police had found a man on the motorway and that Bed and Breakfast accommodation (B&B) should be provided whilst his address in Belgium was located:

Man from Belgium, [reported] missing, and police requesting B&B placement: this was an email from the Emergency Duty Social Worker. The person had been found on a motorway and the police thought that he might have learning disability. (Field notes, shadowing Audrey, 2 August 2011).

The data extract above shows that initial referrals to Kotoka could be a request for risk assessment. Implicit in the police's approach to the social work team was an assessment that the man faced risks if left alone. In this instance, risk was conceptualised as the here-and-now, as a matter that required immediate action by the social work team lest a service user remained in danger. Looking beyond the present, in Kotoka, a risk assessment was conducted routinely as part and parcel of service provision. For instance, the primary document for determining and recording

eligibility for services called ‘Comprehensive Assessment’ had a section titled ‘Personal Safety’ with the following questions as prompts for professionals to ask:

- Have you had any accidents inside your home?
- Are you alone for short/long periods?
- Do you feel unsafe in your home
- Are you frightened to leave your home?

Arguably, the questions above show that Personal Safety was conceptualised as a need because they were an intrinsic part of the needs assessment to judge eligibility for services. The questions above also implied that everyday living involved dangers, intended or not, and irrespective of whether one was at home or in the community. As such, professionals in Kotoka attempted to foresee and predict future harm in their routine interactions with service users during home visits, needs assessments, and/or care plan reviews. Thus every impending change in service users’ lives was associated with risks, which professionals had to forecast and mitigate (Kemshall, 2002; Webb, 2006): this could be around service users’ life course – for instance becoming an adult at 18 years, or reaching retirement age – or there could be adjustments to care packages. It is in this regard that some writers have suggested that preoccupation with risk in statutory services means that risk and needs assessment are now symbiotic (Kemshall, 2010; Warner and Sharland, 2010). Taken from the viewpoints of parents or carers, risk assessments extended the power of professionals into family lives because parents could be told how to keep their children safe, and by corollary, they became responsible for possible harm to their children. In the next section I expand further on this preceding point by presenting some field notes from

observing a meeting between a social worker, Adwoa, and a service user's father, Mr Crabtree.

Risk assessments and caring

Risk assessments created a nexus of responsibility between Kotoka, parents (or carers) and outside agencies, as exemplified by the data extract that I now discuss below. The extract is taken from field notes I made on 22 June 2011. There were two important backdrops. Firstly, Mr Crabtree had been granted a Power of Attorney mandating him to make decisions on behalf of his daughter (it was not clear from the meeting I observed the range of activities over which he had legal powers). The second background issue was that of the Community Alarm. In Kotoka, these were issued to service users to be activated if they or their carers felt in danger. Mr Crabtree's daughter had a Community Alarm because of previous epileptic seizures. In the meeting with Adwoa, Mr Crabtree reported that the alarm was defective; however, he did not think that he could remove it without Adwoa's permission.

1. Mr Crabtree – Second thing [on the agenda] is the Community Alarm system – it is not working. [Mr Crabtree] wants to pull it out and replace it with something else. Engineer has been told.
2. Mr Crabtree – Does not want the alarm but does not [want] to be told that he has been irresponsible for taking the alarm off. Mr Crabtree said that in the past he had been accused, he implied, by statutory services for being 'irresponsible' with his daughter's safety.
3. Mr Crabtree: The alarm is waking people up [even when it has not been activated]: I recall Mr Crabtree saying here that on the Sunday the Community Alarm technician claimed that they called him and

because he did not answer they had to attend to the house. As a result they would be charging Mr Crabtree the call-out fee, which he felt was unfair especially as he was in church and the alarm had erroneously self-activated.

4. Talk about seizures and service user having 'rare' seizures: Adwoa felt that taking the alarm off was a question of risk assessment and that as the service user had 'rare' seizures then Mr Crabtree would be justified in replacing the Community Alarm.
5. Risk assessment required by Maples: I recall Adwoa saying that as Maples provide the sleeping-in care, if the community alarm is removed then Maples would have to conduct a risk assessment on how the removal of the alarm would impact on their services (Field notes, shadowing Adwoa, 22 June 2011).

It is noticeable that at point 4, Adwoa provided the authorisation for Mr Crabtree to remove the alarm, citing his daughter's 'rare seizures' and thereby conceptualising risk as low. Adwoa further indicated that with the removal of the alarm, the private care provider, Maples, would have to conduct a risk assessment as they employed the carer who stayed overnight in the service user's home. In the interaction between Adwoa and Mr Crabtree, there were elements of risk in the here- and-now, such as having seizures, but also risk as prospective, such as what was to be done in the future if harmful circumstances arose.

Moreover, the data extract shows that, once risk was identified by professionals, parents assumed a moral responsibility for their child's safety, even if their child was now an adult, or even, as in the case of Mr Crabtree, a parent had the legal powers to make decisions on their children's behalf. The latter point throws into

sharp focus some legal ambiguities in respect of risk, mental capacity, and caring. Based on the MCA's principle of presumption of capacity, parents (or carers) cannot tell service users how to lead their lives. Yet, as I have demonstrated in point 2 above, Mr Crabtree has in the past been held responsible for his daughter's safety, and he still felt such an obligation during his conversation with Adwoa. Additionally, Mr Crabtree thought that the authorisation for his actions had to be provided by a professional (i.e. Adwoa). Therefore on the present discussion, a conclusion can be drawn that Mr Crabtree's moral duty to keep his daughter safe continued into her adulthood, even in the face of her statutory right to make 'unwise' decisions under the MCA.

The tension between the MCA's unwise decision principle and parental obligation for their children's safety, exemplified above in the case of Mr Crabtree and his daughter, is unexplored in the literature. Unlike the prolific literature on child protection in which it is assumed that families are central to assessment and mitigation of risk (Brandon et al, 2008), with adult services, families' role in safeguarding is less discussed. In the face of policy evolution in adult protection (Law Commission, 2008), the literature on Safeguarding Adults policy and practice tends to focus on guidelines and institutional structures (ADSS, 2005; SCIE, 2011), service users' involvement in risk assessment (Wallcraft and Sweeney, 2011), and how the introduction of new policies, such as personalisation, relates to risk in adult services (Manthorpe et al, 2008). The informal attribution of responsibility to protect adults that accrues from contact with statutory services remains unexplored in the literature.

The aim of Part One of the present chapter was to explain how professionals distinguish between risk and their invocation of the broader safeguarding policy framework. I have begun by showing that risk was considered as part and parcel of

everyday life, as according to the risk society thesis, and ‘safeguarding’ was part of the routine conversations of professionals. My initial surprise at the repeated discussion about safeguarding in Kotoka was to be sustained throughout fieldwork. I observed several meetings investigating allegations of abuse, interviewed professionals about safeguarding practices, and read several local policy documents. Based on these fieldwork observations, in the next section, I discuss how safeguarding policy was operationalised in Kotoka as a further way of showing its distinction from risk assessment.

Localising safeguarding policy

Borough-wide, there were two organisational channels for implementing Safeguarding Adults policy and practice (henceforth referred to as a dual structure). One was the local authority-wide Safeguarding Team – the ST – (discussed in Part Three of Chapter Five); the second was individual specialist services: for example older people, mental health, and integrated learning disability services (Kotoka). Each specialist service in the local authority where I conducted fieldwork had its own system for safeguarding alerts - mirroring national policy; the social work team took the lead: firstly, the Duty Social Worker was the point of contact for all alerts; secondly, the social work team coordinated the subsequent investigative work. In Kotoka all alerts were called Safeguarding Referrals – they came to the team verbally, through reports at reception, telephone calls, or sometimes as documents through the completion of referral forms. On receiving an alert, the Duty Social Worker consulted with the Duty Manager (Monica) whose role was to decide whether the alert should be pursued. At the point of alert, Monica judged whether the alert was credible and, if so, whether it was a criminal matter to report to the police. Another decision that

Monica made (sometimes in conjunction with colleagues) was whether the alert was an ‘institutional concern’ in which case she involved colleagues from the ST.¹⁶

The concept of ‘institutional concern’ was widely used in the service, however a succinct definition was provided by Emma, Assistant Manager of the ST, when I interviewed her:

So [...] we [from the ST] chair some safeguarding meetings but we chair those where, if there’s been a death [which is unexpected], if it’s an institutional concern, if the alleged perpetrator is a staff member [of the local authority] [and] potentially one of our partner organisations (Taped interview, Emma, 4 August 2011).

From the quote above Emma confirmed the borough-wide dual institutional arrangement around Safeguarding Adults policy and practice in Kotoka. During fieldwork with social workers, they agreed with Emma’s distinction between their roles, although some professionals in Kotoka used the term ‘establishment concern’ instead of ‘institutional concern.’ Where there was an institutional concern, the safeguarding process would be overseen by the ST. In the main, because the specialist teams such as Kotoka received referrals, the ST relied on them to be informed of whether an ‘institutional concern’ had occurred. The specialist teams such as Kotoka, on the other hand, had an interest in informing managers within ST because they were more knowledgeable of local and national safeguarding policies.

¹⁶ In Part Three (Chapter Five) I showed that among other duties, the ST’s staff role included writing safeguarding policy, training on MCA best practice and chairing safeguarding meetings. The current discussion about ‘institutional concern’ is one way by which the ST staff drew the contours of their duties vis-à-vis specialist teams such as Kotoka.

Whether supervised by the ST or the social work team, another key decision to make was whether the alert constituted a ‘criminal’ matter, in which case the police were informed. In line with statutory guidance, if the police acknowledged that the information they had received indicated a possible crime then their investigations took precedence. Otherwise, professionals in Kotoka convened a multi-professional Strategy Meeting (SM) to decide whether the alert warranted further investigation and to determine the accompanying task of each professional. It can be seen from the present discussion in the preceding paragraph that the social work team’s Duty Manager, Monica (and her colleagues), had the power to decide the trajectory and category of safeguarding cases. For instance if Monica decided that the alert pertained to criminality, she curtailed the involvement of Kotoka. Thus the general category of ‘safeguarding’ involved several (sub)categorisations by professionals. To illustrate further, at the point of an alert, Monica could (re)categorise the matter as an ‘institutional concern’ or as ‘criminal’, thereby placing the piece of information on a different institutional trajectory. In the next section below, I present data to show how the specific institutional arrangements, whereby responsibility for safeguarding ‘vulnerable adults’ was split between the specialist teams and the ST, shaped categorisations of risks.

Shaping case categories

To contextualise the forthcoming discussion, it is worth outlining some important backdrops to this section. Policy-wise, after safeguarding investigations, statutory services decide whether the alert is proven (or not), and if so, the category of abuse perpetrated (abuse can be financial, physical, sexual, psychological, neglect and ‘neglect and acts of omission’ (DCA, p245). Thus, whether the ST staff or specialist teams chair safeguarding investigations, the abuse has to be categorised. Another

noteworthy background to this section is that decisions about the trajectory of safeguarding cases in Kotoka are made by white women. As explained in the previous chapter, Monica, the (safeguarding) Duty Manager in the social work team was a white woman of Polish origin and all the practitioners in the ST were also white women. Lastly, a commonality between the ST and Kotoka in terms of safeguarding is that all the managers with powers to decide the trajectory of these cases were qualified social workers. Both Assistant Managers in the ST were formerly employed as social workers in Kotoka. Thus there was a close relationship between the social work team and the ST staff. Additionally, because two of the Assistant Managers of the ST worked as social workers in Kotoka, they were (in)formally acquainted with the mental capacity of some of the service users discussed in safeguarding meetings. Below, I present data to show how the dual institutional arrangement on Safeguarding Adults in Kotoka impacted on the (re)categorisation of cases.

The ST staff: (re)categorising safeguarding 'alerts' from historic knowledge

The data presented in this section is from my field notes of a safeguarding meeting chaired by Martina from the ST. During the meeting Martina relied on her knowledge about the service users gained from previously working in Kotoka to (re)categorise the case. There is an underpinning principle in the MCA that assessors should seek the views of the person 'who knows them [person undergoing assessment] best' when conducting formal mental capacity assessments (MCA Code of Practice, 2007; p32). One reason for this advice is that the person 'who knows the service user best' understands their means of communication or their life history and can therefore offer guidance on their possible choices. Furthermore, as I showed during my analyses of CCP in Part Three (Chapter Five), within a multidisciplinary setting, claiming to know the service user best conferred power on a professional to decide service users'

(informal) mental capacity (as was done by the psychiatrist). With Martina, because she worked as a social worker in Kotoka and was acquainted with the family, she too claimed to know the service user best to categorise the safeguarding case.

In addition to Martina, the following professionals were present at the recorded safeguarding meeting: social worker, Annika, a community psychiatric nurse (CPN), and the manager of a private care agency. The meeting was called because of concerns about three service users: Tracey and her parents, Damien and Anouska. They lived with Michael who was involved in a relationship with Tracey. Tracey had children from different relationships who were all Looked After Children (LAC)¹⁷. In the past, Damien and Anouska had reported that Michael physically assaulted all three of them; however, during previous safeguarding investigations, Tracey denied any abuse. Damien was diagnosed with depression and diabetes but refused to take his medication, a matter of concern to the health staff in Kotoka. Professionals at the meeting acknowledged that Tracey and her parents all had capacity to make decisions for themselves. The service users' informally assessed capacity was, however, a source of frustration for professionals in managing the family situation because a care package could not be arranged without their consent. As a last resort, the local authority temporarily relocated Tracey and her parents to Brighton (to escape Michael), which Martina in point 10 below felt was a good thing 'because they have seen a different life.' After the family's temporary relocation to Brighton, Michael followed them, prompting the local authority to return them to their original home. Since the family's return, further concerns have arisen, including one from the police that Tracey was pregnant, implying that the unborn child might be at risk of harm. In

¹⁷ Under the 1989 Children Act a child could become Looked After if their parent(s) voluntarily asked a local authority for them to be accommodated or if sanctioned by a Court.

the meeting from which I have extracted field notes data presented here, Martina (from the ST) seemed to be grappling around for further statutory powers to manage the situation.

1. Martina (Chair) – Purpose of meeting to ‘consider’ investigation, make decisions on alert, listen to the wishes of the service users, to decide who feeds back [to service users].
2. Annika (Social worker) (background of case): Two alerts raised following reports from neighbours that Michael (‘partner’ of Tracey) had been threatening another person. Someone from contact centre raised alert that Tracey had not been attending contact [to see her Looked After Children]; on one occasion bruises seen on Tracey. Damien (Tracey’s father) came and disclosed information.
3. Chair: For the purposes of the minutes MARAC [Multi-Agency Risk Assessment Conference]¹⁸ referral made and support given to them [service user and parents] to go to the police...For the purposes of this meeting there is no further action because they [service user and parents] have refused to go to the police. Let’s go [move on] to the adults at risk [Damien below].
- 4. Damien**
5. Community nurse said that health are concerned about his [Damien’s] general health; concern about whether he is taking medication properly.

¹⁸ MARAC comprises the police, probation, voluntary organisations and all statutory services in the local authority. MARAC receives referrals where a person is deemed at risk of domestic violence. I observed during fieldwork that in instances where professionals considered the risks of domestic violence ‘unacceptable’ the service user’s consent was not sought before a referral was made to MARAC.

6. Chair: All this is coming back to capacity because he has capacity to determine not to take the medication, then there is nothing to do. Could the MHA [Mental Health Act] be used?
7. CPN said that diabetes may be one route.
8. Social worker made the observation that she has seen Damien's capacity fluctuate: he has been able to explain his medication.
9. Chair 'we've known this family for a long time and they have always been chaotic; house is dirty; this is the way the family live.'
10. Chair feels that family being removed from their home was a good thing because they [have] seen a different lifestyle.
11. Review of case planned for three months. (Field notes, shadowing Annika, 14 June 2011).

In the extract above, the safeguarding 'alert' is (re)categorised by Martina from domestic violence, to nothing – 'no further action' – to mental health. This latter point highlights how power is exercised in effecting social categories; more specifically, it shows the close relationship between the social classifications mental health and mental capacity. Martina exercised her power as Chair to direct the classification of this case. The key issue here is point 9, in which Martina showed exasperation with the family's protracted situation. At point 9, Martina asserted her historical knowledge about the family, 'they have always been chaotic; house is dirty; this is the way the family live', and concomitantly a claim of knowing them best. On the basis of her claim, Martina felt mandated to pronounce on the likely trajectory of the case. Because Martina knew the family previously from her period as a social worker in Kotoka, she sought to re-categorise the case from 'safeguarding' to 'mental health' in

order to imbue professionals with more powers to manage the situation. For instance, Martina asked, in point 6, whether the CPN could make a case for the Mental Health Act being drawn upon for diabetes medication to be forcefully administered to Damien. At other times, Martina expressed her frustration by curtailing further professional responses: in point 3, for instance, she ruled that there was no further action required because previously, when Tracey and her parents were referred to MARAC for support, they refused to go to the police to report the abuse from Michael. Martina's moves between points 3, 6, 9 show that, within statutory services where legal powers and duties are attached to specified social categories, the latter could acquire unintended status or implications. For instance, if the CPN made a case for the Mental Health Act, it was likely that professionals would attempt to forcefully medicate Damien, even though he had been informally assessed as mentally capable to refuse medication. The data extract therefore also shows the close overlap between the MCA and MHA. Through this present discussion I have demonstrated how the ST members' close relationship with professionals in Kotoka, as well as their prior knowledge of cases, impacted on the categorisation of safeguarding cases. Building on these discussions, I show in the next section how the ST's role in writing local safeguarding policy affected practice within the specialist teams (for example the integrated learning disability service, Kotoka).

Safeguarding policy and MCA practice in the integrated learning disability service

In the MCA, Safeguarding Adults is a key policy aim because incapacitated adults are also seen as vulnerable (MCA Code of Practice, 2007); therefore, during fieldwork, I sought data on how this is implemented in Kotoka from the viewpoint of the ST's role as local policymaker. In data extract 1 below, Emma (Assistant Manager, the ST) is

reflecting on her previous position as a social worker in Kotoka to explain why the latter received so many safeguarding alerts. Emma distinguished between learning disability service users and ‘physical disability’, and secondly, disabled people from the broader category of ‘private citizen(s).’ Emma suggested that learning disability service users were ‘vulnerable’ and presented ‘a lot of capacity issues’ making them mentally (in)capable of reporting crimes to the police, hence professionals invoked the safeguarding process on their behalf. The connection between safeguarding and mental capacity is explored further in Extract 2 by Abby, Emma’s line manager. Abby noted that where professionals (in)formally believed that a service user lacked mental capacity ‘they are reluctant to allow much risk.’

Extract 1. Yes, simply because the client group is very vulnerable and there are a lot of capacity issues. As I was saying to you earlier, if you or I get mugged we don’t need a safeguarding process, we go to the police and if I had a physical disability I might still just be able to go to the police and deal with it as a private citizen without involving a safeguarding process. But someone with learning disabilities might find it that much harder which is why a lot of these issues come, come to the team [Kotoka]. (Taped interview, Emma, 30 June 2011).

Extract 2. I think that sometimes you know, these best interest decisions that people make are very complex and you know the first principle of the Act say presume capacity but I think professionals are reluctant to allow much risk if they think that there is a possibility, you know that the person lacks capacity. (Taped interview, Abby, 12 July 2011).

The two quotes above could be seen as explanations as to why there were so many safeguarding alerts in Kotoka because arguably, policymakers in the ST expansively interpreted the policy framework. Implicit in Emma's statement was the assumption that learning disability service users lacked mental capacity to ensure their safety and/or seek justice. Here Emma categorised learning disability service users as a distinct group of people who provoked concern in professionals. By linking service users' apparent inability to protect themselves or report crimes to Safeguarding Adults policy and practice, Emma (and her colleagues) made service users' mental capacity central to the process. Through the latter statement Emma echoed statutory guidance that incapacitated adults are, by corollary, in need of 'protection', thereby bringing into sharp focus the need for professionals to 'protect' people (in Chapter Five, I demonstrated through the case study of Amber that one way to 'protect' service users from risk is to increase their care package to ensure supervision at all times). The significance of extract 2, by Abby, is that she confirmed that the process of adult protection began with an informal assessment of capacity because, if professionals had doubts, they constrained service users' actions. The two data extracts above also suggest a wide(r) interpretation of the concept of safeguarding. For instance, arguably, Emma imbued safeguarding with therapeutic qualities by her statement above: people classified as learning disabled needed help to access the justice system and this could be provided once the broad policy framework had been invoked. It is in relation to this latter point that Buchanan (2013) has argued that due to tightening eligibility criteria, safeguarding could displace traditional social work with service users by acting as a gateway to services.

From the viewpoint of professionals in the ST, the local dual institutional

arrangement on Safeguarding Adults policy ensured the centrality of formal mental capacity assessments to the process. To support these claims, staff from the ST directed me to two separate policy guidance documents they had written. For purposes of anonymity, I have withheld the titles of the documents. The first document was written in March 2010 as guidance for chairs of safeguarding meetings. Little prominence is given to capacity in this guidance – for instance, there is no explicit reference to mental capacity. Instead the word consent is used: ‘Consent to investigation – is there a public interest need to investigate?’ In contrast, the second document, authored in March 2011, about empowering service users in safeguarding investigations advised professionals to assess mental capacity, if in doubt:

If there is a question of capacity regarding the individual’s ability to understand and participate in the safeguarding adult process, protection measures, consent to information sharing and investigation, a capacity assessment must be undertaken as soon as possible (capacity assessments must be time and decision specific).

There was a discrepancy between the two documents because, whereas one referred explicitly to capacity, the other pointed to consent. This is significant because theoretically capacity precedes consent; hence the rationale for mental capacity assessment is to decide whether people can consent. In this respect, the March 2010 document which referred to consent was either presuming that all service users would have capacity or that capacity did not matter to the process. In the course of my interview with Emma, the March 2010 document which referred to consent was discussed. She explained that capacity was implicit in the notion of consent; however

sometimes the former could be impaired by the stressful condition that service users had been placed under:

There will be things like ‘do they consent to the investigation.’ Now implicit in that is do they have capacity to consent to the investigation? [...] and of course capacity in a safeguarding situation can be a slightly different thing ‘cos if someone usually has capacity but they are severely intimidated, for example, then perhaps in this circumstance they lack capacity (Taped interview, Emma, 30 June 2011).

In the above interview quote, Emma provided another conceptualisation of mental capacity by suggesting that ‘intimidation’ could impair a person’s ability to make decisions. The quote from Emma, in addition to the documents and interview data from Abby presented in this section, show a complex picture of mental capacity and safeguarding policy within the ST. Firstly, the two ST staff (Abby and Emma) agreed that learning disability service users were vulnerable because of their likelihood to suffer harm as a result of their incapacity to protect themselves. However, the policy documents reflected a contrasting picture from the managers’ views in that there were no specific requirements for capacity to be assessed during safeguarding meetings, although one document carried the proviso ‘if [capacity is] in doubt.’ One explanation for the discrepancy between the interview data and policy documents might be that the latter was meant as generic guidance whereas the interview quotes were answers about learning disability service users (who are presumed in the MCA as more likely to lack capacity.) Finally, Emma’s quote suggested that in adult protection, service users’ mental capacity to consent to their participation in an investigation was not the

primary concern of professionals. The policy document, authored in March 2010, provided a public interest test – ‘Consent to investigation; is there a public interest need to investigate?’ – meaning that professionals had some discretion on whether service users’ mental (in)capacity should be taken as paramount in safeguarding investigations.

To conclude this section on the institutional arrangements on Safeguarding Adults in the integrated team, I make some remarks on the broader implications of my observations in Kotoka. Whilst ‘safeguarding’ was regularly invoked and I observed many meetings and conversations on the subject, I rarely witnessed service users participating in the process. My findings therefore echo the following commentary by Fyson and Kitson’s: ‘it is perhaps worth reflecting that safeguarding often appeared to be being constructed as a professional “problem” to be solved, in the course of which service users may sometimes cause irritating additional difficulties’ (2012; p101). Whilst a helpful contribution, Fyson and Kitson’s point does not fully explain the discrepancy between professionals’ anxiety to ‘protect’ service users whilst also excluding the latter from the process. A fuller explanation may lie in socio-cultural perceptions of risk: for instance my fieldwork commenced immediately after the airing of a television documentary reporting the abuse of learning disabled service users in a care home. During fieldwork I found the documentary overshadowing the work of professionals, making them more sensitive to risk perceptions. Socio-culturally, certain people elicit concerns about safety, and translated into statutory social care, attempts are made to mitigate risks such service users face (Kemshall et al, 1997). That the Panorama programme had such a profound impact on the political debates on the safeguarding policy framework reinforces the argument that risk interpretation and sensitivity emanate within a socio-cultural milieu (Douglas, 1985;

1992). Paying attention to socio-cultural ideas, I now discuss a surprising finding from fieldwork. Some service users in Kotoka were neither classified as learning disabled nor mentally incapacitated; yet, they evoked concerns about their safety and received substantial care packages.

Liminality: ‘vulnerable adult’, mental (in)capacity, and risk

Using the concept of liminality as an analytic tool, I describe the situation of Dwayne and Alan, respectively black and white males who both had folk status in Kotoka. Widely used in the anthropological literature to signify rites of passage in certain cultures, liminality is useful in conceptualising contingency: ‘In liminality there is no certainty concerning the outcome [...] events and ideas, and “reality” itself, can be carried off in different directions’ (Thomassen, 2009; p5). Liminality is a helpful heuristic device in this section because both Dwayne and Alan occupied an unusual categorical space: they were not viewed by professionals as either learning disabled or mentally incapacitated, yet both provoked anxiety among professionals about their safety. Two sharply contrasting models of safeguarding were employed in managing their care. In the case of Dwayne, professionals supported his detention in a psychiatric unit under the 1983 Mental Health Act (as amended in 2007), whereas with Alan, he was encouraged by professionals to partake in advocacy services organised by the local authority.¹⁹ Dwayne and Alan’s cases may therefore also be seen as indicators of unequal treatment that result from ethnic and disability categorisations.

¹⁹ This form of advocacy initiated by local government has been termed ‘closeness to power’ (Buchanan and Walmsley, 2006; p136) with some writers questioning its underpinning claims to empowerment (Redley and Weinberg, 2007).

To attain my aims in this section I will analyse the following data: field notes of a multi-disciplinary meeting held to discuss his behaviour, my Reflective Diary entry following a home visit with Rose (Alan's social worker) and Rose's Comprehensive Assessment of Alan's needs. To analyse Dwayne's situation using the concept of liminality I will present two sources of data. The first source of data is two official minutes of Complex Cases Panel (CCP) meetings; the second data source is my field note recordings of a CCP meeting that I observed on 12 July 2011 at which he was discussed.

Dwayne: categorising liminality as risk

Dwayne, a young black man, was not known to statutory service until the age of 17. Living together as a 'single parent' family unit, it was on the cusp of Dwayne's adulthood that his mother contacted children's services to report her struggles with managing his relationship with local 'gangs'. For reasons unclear to me, he was assigned to the Disabled Children's service. By the time Dwayne became known to professionals at Kotoka, he was involved with the police for violent offences. Within Kotoka, Dwayne was seen as a clever man. The consensus on Dwayne's cognitive capacity is evidenced by the two data extracts (official minutes) below from separate CCP meetings:

Extract 1. Quite high functioning. Needs to learn how to behave (CCP minutes, 28 June 2011).

Extract 2. ?Autism. Has capacity to make decisions and say where he lives. Mum very anxious about risks [...] Easily influenced, does not comply or engage with services [...] (CCP minutes, 12 July 2011).

Both data extracts above evidence that professionals at the CCP meetings highlighted Dwayne's high cognitive capacity. The query in data extract 2 about whether Dwayne could be categorised as autistic – '?autism' – is worth further exploration in the context of data extract 1 where it is said that '[Dwayne] [n]eeds to learn to behave.' As professionals struggled to explain or understand Dwayne's apparent 'anti-social' behaviour, various possibilities were sought, including psychopathology (in this case autism). Furthermore, in data extract 2, it is said that Dwayne's mother shared professionals' anxieties about his 'behaviour' – 'Mum very anxious about risks' – thereby reminding us that, as in the case of Amber (Chapter Five), in Kotoka, the interests of families and professionals periodically aligned in the management and pathologising of (mis)behaviours as 'risk'.

Continuing with Dwayne's life story, by the time he was allocated to a social worker in Kotoka, he was facing a police charge for 'violent behaviour'. At the ensuing trial, the judge referred Dwayne to a psychiatric hospital for a mental health assessment whereupon he was 'sectioned' under the Mental Health Act (MHA) on reports that he 'threatened' to kill his mother. Subsequently when told of his right of appeal to a Mental Health Tribunal (MHT) against the section, Dwayne acquired a solicitor on his own accord. He was discharged by the tribunal because of lack of evidence of mental illness. The data below is extracted from my field notes of CCP meeting on 12 July 2011 where Dwayne was discussed following his discharge from hospital. I recorded concerns about the risks Dwayne faced in the community and belief among professionals that his mental capacity prevented any mitigating care planning:

Max implied at this point that it would have been better if Dwayne had not won his MHT appeal. There was a discussion about the appeal process. Apparently members of the MHT said that they thought that by discharging Dwayne they were exposing him to more risks and the possibility of him ending up in the criminal justice system, nevertheless they felt that they did not have the power to detain him [...] DOLS²⁰ is out of the window because he has capacity. Has capacity to make decisions on accommodation. Refusing to go to residential placement. [Dwayne] wants to get out of hospital; lives in Kotoka [and wants to remain here]. Aspirations: wants to go to college, wants to live in a hostel. (Field notes, observing CCP, 12 July 2011).

Dwayne presented complex legal and moral quandaries for professionals around risk. His mother was anxious about his safety and professionals similarly felt that he was 'vulnerable' and would become further involved in violence on discharge from the Section. Based on these assessments, professionals grappled around for legal powers to 'protect' him as indicated in the data extract above. Care planning for Dwayne's 'protection' was, however, complicated because he clearly demonstrated capacity, as exemplified by his choices of accommodation, a solicitor, and his avowed aspirations to go to college. As such, a care plan could not be arranged without Dwayne's consent. Furthermore he did not have a mental illness so professionals could not draw

²⁰ DOLS refers to Deprivation of Liberty Safeguards and is part of the MCA. DOLS legalises the detention of people assessed as lacking mental capacity for 'treatment and care'. The DOLS Code of Practice proposes it as 'protection' for 'vulnerable' people (Ministry of Justice/DOH, 2008; p9), thereby linking the MCA to safeguarding. DOLS mandates institutions offering care or treatment (such as a care home or hospital) to apply to a local authority for licence after exploring 'least restrictive' options besides detention (Dwyer, 2009).

on MHA powers to enforce a care plan. Thus without any legal powers mandating Dwayne to follow a care plan, professionals felt powerless. This led Max (Head of Service) to make the morally dubious point in the above data extract that Dwayne would have been better off in a psychiatric unit, notwithstanding his mental capacity and the potential illegality of detaining a mentally healthy person under the MHA. Noticeably, despite Dwayne being ‘high functioning’, during the CCP meeting of 12 July 2011, professionals were unanimous on his right to services even though the eligibility criteria in Kotoka were ‘critical’ and ‘substantial’.

One explanation for Dwayne meeting the eligibility criteria, notwithstanding his ‘high functioning’, was the application of the concept of ‘vulnerable adult’. On 21 July, I was shadowing Adwoa, when Danielle (Assistant Social Work Team Manager) and I started a conversation about Dwayne. Danielle was unaware that I was present at the CCP I have just discussed. She initiated the conversation with me perhaps as a result of exasperation with managing the case or because she felt I was an expert, given my research interests. Below are excerpts of my field notes below about the conversation:

Danielle said that Dwayne met the [eligibility] criteria because he was ‘vulnerable’ so this led me to ask whether ‘vulnerability’ was another eligibility criterion. Danielle then explained about FACS – did I know what it was? – I said that I did not fully grasp her explanation of where vulnerability came in the eligibility criteria. Nevertheless her explanation of the interaction between FACS, eligibility criteria and ‘vulnerability’ led her to say ‘that’s why people fall through the cracks’. (Field notes, 21 July 2011).

In the field notes above, Danielle's phrase 'people [service users] fall through the cracks' can be inferred as referring to liminal spaces because she is suggesting that those service users did not fit any categories. Furthermore she enveloped liminality within the concept of vulnerability. In Kotoka, 'vulnerability' therefore acted as an(other) eligibility criterion for services but 'vulnerability' was operationalised as potential harm to the body. It was unlikely that someone who claimed to be poor, or was 'confused' about the spiritual essence of life, would be provided services: there had to be a threat to, or by, the embodied person. For instance, in the case of Amber, who was considered to have mental capacity and where doubts were expressed about whether she could be classified as learning disabled, her social worker Rose described her as 'vulnerable'. In the data extract below, Rose explained why Amber became known to the service:

I asked then how Amber had become known to the service. Rose said that she had become known to the service as a result of being a 'vulnerable adult' through the interaction between her being in the mental health system and the report from her family that she had been 'sold' for sex (Field notes, shadowing Rose, 13 July 2011).

Thus in Kotoka one way that professionals addressed the needs of service users who could not be fitted into the social category of learning disability or mental incapacity (i.e. liminality) was through the operationalisation of the concept of vulnerability. Dwayne and Amber were not regarded as fitting the classification 'learning disability' yet they offended social norms: the former did not 'learn to behave' and the latter was deemed to be sexually profligate. By being classified as vulnerable, Dwayne and

Amber became subject to control through complex care packages. With Dwayne one dimension of control was his withdrawal from everyday life to keep him safe. In sharp contrast to this, with Alan, who I now discuss, every effort was made to avoid his social exclusion, even though he engaged in racist behaviour and threatened some staff.

Alan: dealing with liminality through closeness to power

Alan was well-known within the service because he was a member of the self-advocacy group formed by the PCP Coordinator to train social workers in user perspectives on PCPs. Alan's self-advocacy role in the integrated service was discussed when I visited him with his social worker Rose, as I later wrote in my Reflective Diary:

We were talking about the PCP Coordinator in the office who runs a training program that is delivered by service users to social workers about how to do PCP assessments. Alan remembered that he was delivering some of the training (starting 11 July) and invited me to attend (Reflective Diary 14, June 2011).

One of the reasons for Alan's role as a self-advocate (as shown from the data extract above) was his social presentation. In his Comprehensive Assessment, Rose recorded that Alan could understand all verbal communication, he could read, and he could also self-advocate. The relevant passage from the Assessment form is cited below:

Alan has a good level of verbal communication and understands everything that is said to him. He is confident of giving his views on all subjects and will let professionals know [...] Alan can read simple texts and look for words that he recognises to get the overall meaning. (Comprehensive Assessment Form (Alan), 13 October 2010; p3).

The data extract above from Alan's Assessment form is Rose's (informal) assessment of his capacity. In the first sentence, the social worker conceptualised mental capacity as communicating (as I have discussed in Part Two, Chapter Five). The data extract above also evidenced that Alan displayed capacities which defied the connotations of the labels of learning disability or incapacity: Alan could understand, remember, explain complex concepts, and communicate his thoughts. On 24 August 2011, I attended a Professionals' Meeting with Rose, which was arranged to discuss Alan's apparent racism to staff in his supported accommodation. The backdrop to the meeting was the civil disturbance in London during August 2011, which resulted in arson at several London local authorities, including the site of my fieldwork. Coinciding with the day of civil disorder, support workers had promised Alan and his friends a street party but this had to be cancelled in the face of the disturbances. Eight professionals were in attendance at the meeting I observed including staff from Kotoka: Tough (trainee clinical psychologist), Rose (social worker), Morris (domiciliary care coordinator), and staff from the Housing Association (owners of Alan's accommodation). All professionals had known Alan for a while, and believed they had insight into his level of understanding. Below are extracts from my field notes of the meeting:

1. Riots, police decide that planned street party should be cancelled because they could not provide officers...Alan would not agree with the police's stipulation, became agitated and verbally abusive. On seeing the reports of the riots on TV he claimed that the riots were caused by black people and blamed them for cancellation of the party...remarked whenever he saw TV 'you see it's the black people doing it.' When black support staff approached him he would respond 'F-off you black so and so.'
2. Does he understand it [his racist behaviour]? Professionals from Housing Association at the meeting felt that Alan understands; that he is aware that his opinions are racist – 'that it is measured [premeditated]'. Maxine [support worker] said that another tenant has told her that Alan has told him that if they got together they could kick out 'all the monkeys [black staff]'.
3. Morris: What about his capacity to understand? We [referring to the group of professionals at the meeting] know that he has capacity to understand what he is doing; we know that he knows what he is doing.
4. At this point of the meeting I [Godfred] made these observations in my notebook which I cite verbatim here: 'Care Coordinator [Morris] to my surprise was defending Alan. Said that if he [Alan] does not want black staff then it's the role of the service to find white staff – 'that's diversity'.
5. Tough: PCP [proposed] Yes last time [when Alan manifested such behaviours] he was referred to the psychiatrist so maybe medication

can [also] be helpful (Field notes, Professionals' Meeting, 24 August 2011).

At line 4, Morris (a black male staff) defended Alan by reinterpreting Alan's racism in the official discourse of 'diversity.' The fact that a black person is employing the discourse of 'diversity' to defend white racism is worthy of note because the official parlance is ostensibly designed for the opposite: to 'protect' black people from statutory discrimination. Throughout the meeting Morris was keen to have the charge of racism re-categorised as one of psychopathology. In this, Morris was successful because the meeting decided that, rather than charge Alan for breaking his Tenancy Agreement because of racism, PCP work would be carried out and medication administered, as was done in this case last time (point 5).

The data on Alan and Dwayne illustrated two sharply contrasting responses to 'high functioning' service users with capacity who nevertheless were deemed to present risk. In the case of Dwayne, he was categorised as a 'risk' although he was neither learning disabled or mentally incapacitated and attempts were made to confine him away from society; firstly through the Courts, and secondly, through the mental health system. Alan's case was entirely different; professionals attempted to maintain his connections with established networks, including self-advocacy in Kotoka. Although both were considered vulnerable by professionals, Dwayne's potential to cause physical harm provoked more anguish and he was considered more of a risk. The professional responses were thus markedly different. In Dwayne's case, the head of service, Max, thought his confinement in hospital would have been better, whereas in Alan's situation, there was a plea for 'diversity' and medication.

Up to now I have taken the view in this chapter that risk is a given in social care and on this basis, I sought to explain on the one hand, how moral responsibilities for 'protection' accrued to service users' social networks (including their parents and carers). On the other hand, I have also shown in this chapter that practice in Kotoka, under the ever-present shadow of safeguarding practice, was curious. Under the category and statutory duty of safeguarding, professionals moved along a continuum of non-intervention (as in the 'no further action' stipulation by Martina in the case of Tracey and her family), full incarceration (Dwayne), and a middle ground of 'protecting' even where service users engaged in socially and morally frowned-upon activities (as in the case of Alan). At times in Kotoka, professionals moved along this continuum in the same meeting (in the case of Tracey, for instance, Martina moved from non-intervention to confinement with her appeal to the MHA). The issues that accounted for professional decision-making about risk discussed here can be summed up thus: a combination of power, historic knowledge about service users, moral positioning, and the configuration of services between local authorities as 'purchasers' and private agencies as 'providers' of care. One other issue which provoked my inquisitiveness as an 'outsider' in Kotoka was ethnicity because it was apparently invisible to professionals yet evident to me as a researcher. Professionals were uneasy about discussing ethnicity, yet it featured prominently in some cases and institutional spaces such as CCP or safeguarding meetings. In what follows (Part Two) I discuss practice with minority service users in Kotoka.

Part Two. Wrestling with cultural differences: professional practice with ethnic minorities

Presenting and analysing data about practitioners' understanding of the concept of ethnicity, I have framed Part Two around the overarching theme of 'culture as deficit' (Park, 2005). Given the multi-faceted conceptualisation of 'ethnicity' here, in Part Two, I use 'culture', 'ethnicity', 'minority', and 'Black and Minority Ethnic (BME)' interchangeably.

The (in)visibility of ethnic minorities

In a statistical analysis of the 2001 census, a local strategic planning paper described the ethnic make-up of the borough comprising Kotoka thus:

The most demographically distinguishing feature about [the borough] is its combination of particular ethnic groups. Compared to the 'typical' situation in Outer London boroughs it has a large 'Other White' group (12.9%), a relatively high, though small, Bangladeshi group (1.3%) and, though less exceptional, Black Caribbean's (5.3%) – all %s from the 2001 Census figures. The 'Other White' group is composed largely of Greek and Turkish Cypriots and Turkish. (Local Implementation Plan, undated; p5).

Specifically within the Kotoka, ethnic diversity was given prominence. On entering the reception area for instance, I noticed a large body of literature publicising services

written in minority languages. There was also a concerted effort to engage BME advocacy groups in service provision by linking them to service users. For instance, on a visit to a local carers centre with close connections to the local authority, I collected assorted literature signposting service users to BME social care organisations. Regarding my encounters with BMEs (which I broadly define to include white non-British people), I met very few service users fitting such a classification. I did not meet any black service users; however, I met one service user from Poland who had recently immigrated to the UK. As I illustrate below using a data extract from my Reflective Diary, initially, the invisibility of ethnic minorities caused me some anxiety, given ethnicity is a key substantive concern of my research:

I have returned miserable and downbeat because I really can't figure out the overall strategy of my research yet. I am supposed to be finding out MCA assessments and ethnicity and yet I have barely seen an assessment let alone observed a BME service user! (Reflective Diary, shadowing Ofira, 21 June 2011).

The data extract above shows how in my reflections on fieldwork, I became concerned that I was not meeting the substantive aims of my research because of the invisibility of ethnic minorities. In an attempt to remedy the situation and observe ethnic minority service users in Kotoka, I spent many hours in the waiting area. Sometimes I arrived early to hang-out in the reception area because I felt that being the 'face' of the service, the use of that space reflected the image that the service wanted to project to outsiders. In the reception area I rarely saw black or other ethnic minority service users although I saw many professionals who fitted the latter

descriptions. Another noteworthy issue is that only one of the service users I visited with professionals was an ethnic minority (the Polish family described above). My findings described here about the invisibility of ethnic minorities in Kotoka, therefore, echo recent calls for empirical explanations of ‘missing bodies’: ‘there has been limited sociological or other attention to the [in]visibility of bodies, including their deliberate erasure, their unanticipated disappearances and elisions, and their celebratory objectification.’ (Casper and Moore, 2009; p9).

Related to the (in)visibility of ethnic minority service users was that professionals appeared to struggle with understanding and articulating the concepts ‘ethnicity’, ‘ethnic minority’, or ‘Black and Minority Ethnic’. To elucidate further on this point, I now present a data extract from an interview with Jessica, a white occupational therapist, who had worked in the local authority since 1991. The interview was an uncomfortable experience because Jessica seemed reluctant to answer any questions, and she asked not to be tape recorded. It was therefore a breakthrough of sorts when Jessica took an interest in my research and questioned me about the concept of an ethnic minority:

[Jessica] mentioned that she thought that my project was worthwhile and she asked what I thought an ethnic minority was – did I think a Greek person was a minority? I said that her question exposed the complexity of the concept and said that I had been asked the same question at the ethics review. Jessica then said that she had not worked with many minorities whether in her role as an OT or as a Best Interest Assessor. She said that she tended to work with whites and Asians but a majority of the service users are white. (Field notes, 02 August 2011).

Of particular interest to the present discussion is Jessica's question about whether Greeks constituted a 'minority' because she appeared to accord majority status to Asians, even though in popular usages and by the census data I presented earlier, the category 'Asians' referred to minorities (Cole, 1993). However, at the same time, Jessica also exposed the limitations of the nomenclature 'ethnic minority' because in certain spaces and locations, a minority group would be the majority if more numerous. This latter point also highlights the difficulties in operationalising the concept of 'ethnic minority' in empirical research because the researcher and their participants may not share the same views of the meaning of 'minority' or 'majority'.

Being a black male, I had hypothesised that ethnic minority professionals would display a better understanding of the concept of ethnicity. However in my fieldwork, there was no relation between a professional's ethnicity and whether they were willing to (or could) explain ethnicity and its related concepts. In the main, professionals were uneasy about discussing ethnicity; some denied having case responsibility with ethnic minority service users even though I had observed the contrary. My fieldwork experiences in this regard echo previous findings by Keating and Robertson (2004) and Gillies (2011), which I discuss briefly to contextualise the rest of the chapter. From their mixed-method study using focus groups and interviews of mental health professionals and ethnic minority service users and their carers, Keating and Robertson (2004, p444) found that 'A striking issue to emerge from professionals was that there seemed to be a fear of talking about issues of 'race' and culture in a safe and honest manner'. Similarly, in her ethnography of a Pupils Referral Unit for young people excluded from secondary school, Gillies (2011) found an over-representation of black children at the same time as professionals were

unwilling to discuss issues of 'race' because of a mistaken assumption that they would be accused of racism.

In the next section, I discuss the question of BMEs' (in)visibility through the prism of culture, an allied concept to ethnicity. I draw attention to culture because, within Kotoka, it was not so much that concerns emanated around the embodied category BME. Professionals seemed anxious about what the category BME signified in terms of people's (risky) lifestyles rather than their presence *qua* presence. Thus BMEs were visible around discussions about risk.

Making people visible: culture and the presumption of risks

At the time of fieldwork, all the cases that the integrated learning disability service had initiated under proceedings in the Court of Protection (COP) for service users to be removed from their families involved people described as 'Asians' by Jo, a manager. My understanding of the legal proceedings developed from two main sources: routine conversations with professionals and a taped interview with Jo, who I have described previously in Chapter Five. According to Jo, when senior managers at Kotoka realised that all the cases submitted to COP involved only 'Asians', there was consternation. In the data extract below, Jo reflected on a meeting called to discuss the cases in COP:

As a management group we were of like 'oh we've got three people at that level of COP stuff with mental capacity and Best Interest and they've come from an Asian background' and so sort of we all looked round the room and sort of 'oh OK I'm Italian but I'm not Asian there's another person who's sort of'...we were all white European at that time as a

management group you know. We were making decisions on families that weren't from the white European background you know you question yourself, you have to. (Taped interview, Jo, 4 August 2011).

In the quote above, Jo recounted that as a 'management group' senior managers were alarmed at the realisation that all cases to COP involved 'Asians'. In response there was a meeting held – 'like a group supervision' to discuss the cases, but as the quote above shows, that meeting provoked more anxiety because managers realised that all of them were white. One reason for the developments discussed above was that there was arguably a pre-occupation with surveillance of ethnic minorities – especially 'Asian' families - in Kotoka.

The case of Nima can be used as an illustration of one aspect of surveillance. According to Adwoa, a social worker, local authority-employed staff reported that Nima's father stopped her from attending day care services, and he had also been abusive to staff. Adwoa and a colleague were asked to investigate the report. Initially Nima's father told the two professionals on the home visit that Nima no longer wished to attend day care. Explaining further, Adwoa said that when she challenged his account Nima's father changed it and said that Nima had reported being hit by another service user. The implication here was that Nima's father was protecting her from other service users. Professionals did not believe him and were suspicious that he was abusing Nima at home. In response domiciliary care services – 'dom care' – were arranged to 'monitor' the home situation:

[Adwoa] intimated that 'dom care' had been arranged as a way of the local authority observing the home for safeguarding purposes. I recall that

when we discussed this I felt ‘this is what we used to do in children’s services – infantilisation’. Sitting here now I wonder whether there is an emerging convergence between children and adult learning disability practice with safeguarding the course of convergence. (Field notes, shadowing Adwoa, 21 July 2011).

The noteworthy aspect of the data extract above is that domiciliary care was arranged to observe the family home even though this was not the explicit aim of the service. Whilst Nima’s case is one illustration of surveillance, in other cases, professionals observed BME families’ interaction and reported what they deemed ‘suspicious’ behaviour. During one session of shadowing Audrey (social worker) when she was on Duty, a Support Worker emailed to report possible ‘financial abuse’ of Kiela (a service user):

The email from the Support Worker reported that when Kiela’s father had visited them Kiela requested £10 to buy take-away to eat with her father and no change was submitted although the receipt indicated cost of £8.60. I felt that the Support Worker was hinting at “financial abuse” by the father but it is an example of what may constitute ‘governing at a distance’ and the surveillance of service users. It also shows the extent to which safeguarding could constitute control. On this occasion Audrey felt that there was no need for the information [investigation] (Field notes, shadowing Audrey, 02 August 2011).

Some implications can be drawn from the data extracts I have presented in this section. In no other instances during fieldwork did I hear or observe that services had

been arranged for a white service user to ‘monitor’ their home. Nima and Kiela’s cases, therefore, provide prima facie evidence of surveillance of ethnic minorities. Furthermore, the data extracts can be used to support an argument that professionals’ assumptions about certain cultures, together with their discretionary use of power, could alter the trajectory of cases. In Nima’s situation, Adwoa and her colleague followed up their suspicions that her father might be abusing her and arranged surveillance in the form of ‘dom care’, whereas Audrey ignored the hint of financial abuse in the Support Worker’s email about Kiela and did not conduct a follow up investigation. Thus stigmatisation matters because it impacts on the service packages that professionals implement for service users taking into account the care/control function of statutory services. Altogether the topics discussed in this section point to the emotion of fear (Zinn, 2006) that certain people and cultures elicit in professionals, leading to risk evaluations. Through this present discussion, I am drawing attention to the transparency of institutional practices in Kotoka geared at ‘protecting’ people such as occurs in the CCP. As a final note, the data presented in this section highlight how ethnicity was simultaneously present and absent from Kotoka. Ethnicity was invisible because, as demonstrated by the data extract involving Jo, it was not always apparent that all managers were white or that ethnic minorities were over-represented in ‘complex’ cases.

Policing the visible: ethnic minorities and CCP

A part of the integrated service in which ethnic minorities were disproportionately (and arguably more visibly) represented was at the CCP. As a researcher observing CCP I heard more instances of service users’ culture and ethnic origin being discussed than when I listened to routine conversations between professionals in the office. CCP meetings may therefore be conceptualised as material and temporal safe spaces for

discussing ethnicity within the context of risk. Of the CCP meetings I witnessed, there were relatively more unprompted references to the dimensions of culture: for instance, to the food service users ate at home – ‘he is no longer eating his mum’s Greek food’ – or people’s origin – ‘24 year old Indian male’. At other times people or ethnic groups were stereotyped - ‘It’s quite a cultural thing within the Asian community’. Arising from these discussions about lifestyles, at CCP meetings, I was able to discern service users’ ethnicity from professionals’ narratives. My assignment of such service users’ ethnicity is defensible, especially given the fact that I rarely encountered ethnic minority service users in Kotoka. However, it is also potentially problematic because those I have categorised may not regard themselves as BME if I asked them (Bradby, 2003).

Nevertheless my research, which is committed to principles of social justice, would be on dubious ethical grounds for two main reasons if I neglected to report that where stereotypes were deployed by professionals, the service users in question appeared to have non-English (or British) sounding names. Firstly, analyses of the minutes from CCP show that a disproportionate number of names were non-English sounding – an intrinsically important finding. Secondly, the list of names in CCP arguably reflects practitioners’ attitudes towards culture in Kotoka and this needs reporting. As proposed by Aspinall (2001), researcher-assigned ethnicity is justified if there is evidence that ethnic classification is leading to unequal treatment:

There remain only a few contexts in which such [researcher] assignment [of ethnicity] can be justified from a conceptual viewpoint. They include the need to obtain the wider society’s perception of ethnicity, as exemplified by Singh, Croudance *et al* (1998)’s study of risk of

compulsory admission, in which a measure ‘specifically of *socially perceived ethnicity*’ or the way ethnicity is constructed in everyday social interaction was required.’ (Aspinall, 2001; p839; original emphasis).

In one exceptional case in CCP, on 26 July 2011, during a discussion of someone with a non-British sounding name, ethnicity intersected with class. Below, I reproduce a field notes extract of my observations of the CCP meeting. The exchanges I recorded were between Audrey (social worker, Black British), Sandra (Assistant Social Work Manager, Turkish) and Max (Head of Kotoka, White British) about a female service user called Mo. Before the CCP meeting I knew about Mo because she had, fortuitously, come up in a conversation I had with Audrey on 22 July from which I had obtained Mo’s biography. Mo became known to the service when professionals found that her mother kept her in a ‘darkened room’. When asked to explain the rationale for her actions, Mo’s mother said that she kept her in a dark room to prevent her coming into contact with stimulation as she believed that sensory perceptions aggravated Mo’s epilepsy.

After a safeguarding meeting, professionals wrote to Mo’s parents imploring them to desist from their actions. When parental ‘cooperation’ was not forthcoming, the local authority initiated legal proceedings for judges to decide whether her parents’ actions were in Mo’s ‘best interest’. Authorisation was granted by COP for the local authority to remove Mo from her parents’ care, but perhaps one of the issues that affected the judges’ decision was that the local authority undertook to find Mo a local placement were the COP to authorise her removal from home. As a result Mo no longer lived with her parents. Audrey was her social worker throughout the duration

of court proceedings. During my conversation with Audrey on 22 July, I had asked her about Mo's ethnicity and noted the following in my field notes:

I asked Audrey whether there were any cultural issues. She said in response that Mo's parents said that they could not speak English even though mother was once a teacher and father a housing officer (Field notes, shadowing Audrey, 22 July 2011).

Based on the data extract above, by the time of CCP at which I recorded the interactions between the professionals, below, I knew therefore that Mo's family were at the very least not 'White British'.

1. Audrey - Alternative placement being sought. Audrey said that she has contacted manager of Alexander Road [another provision].
2. Max – So Mo is still in Pinetree [residential placement]. But we need to keep this up because we do not want to lose parents' cooperation.
3. Sandra – Can Mo talk? Has she got an advocate?
4. Audrey [in response to Sandra] – She can't [talk] but enjoying it [current placement].
5. Max – Would be helpful to have an IMCA [Independent Mental Capacity Advocate]²¹ involved
6. [Current placement] Costs £2000

²¹Where people are assessed as lacking mental capacity, they have a right to IMCA services in the following: changes in accommodation, medical treatment, safeguarding investigations, and applications under the DOLS.

7. Max – Supported living means that family [would] feel they have control.
8. Max – And culturally? [Max was asking whether the current placement met Mo's cultural needs]
9. Sandra – No its middle class White British (Field notes, observing CCP, 26 July 2011).

From his response at point 8 above, where Max asked 'and culturally?' it seemed that like me, Max also believed that Mo (and her family) were an ethnic minority family. Sandra's response at point 9 that the family was 'middle class White British' is interesting in a number of ways. For one thing she was not acquainted with the case (Danielle was supervising Audrey on the case) so Sandra could here be interpreted as assuming the service user's ethnicity and class from the preceding discussion about Mo's parents. In one of the few qualitative studies involving 'Black Middle Classes', Rollock et al found that BMEs firstly associated class with whiteness and secondly, they conflated assertiveness and accent with middle classness: 'Accent is conflated with comportment, in this case composure and politeness as an embodied form of capital, along with persistence and knowledge that enables her [research participant] to take her complaint to the highest channels and obtain the outcome she seeks.' (2011; p1087).

Based on Rollock et al's findings, a more plausible explanation for Sandra's answer in point 9 is that Mo's parents were displaying behaviours (assertiveness, insistence on their rights as parents) associated with white middle class people in Kotoka. For instance, according to Audrey, Mo's parents challenged professionals' decisions at every turn, and as the data extract above suggests, Mo's parents have

continued to do so since her removal from home. Mo's parents' persistent challenge of professionals is exemplified further by point 2, where Max urged professionals to 'keep this up' (i.e. attempts to find her a local placement) to maintain Mo's parents' co-operation. Given the conflation of whiteness with middle classness (Archer, 2011), Sandra's presumptions about Mo's parents' class are explicable, especially given how other professionals described the family. Mo's parents' advocacy was in sharp contrast to some BME families (such as Ibrahim discussed under 'Families: threatening service users' in Chapter Five) who, on being presented with a letter from the local authority's legal department, offered to 'co-operate' with professionals.

The analysis of the CCP discussion about Mo shows how class, ethnicity, gender, parental rights, and professional power combined to affect service users' care in Kotoka. Furthermore, they show that at the coalface of practice, professionals assigned ethnicity on the basis of visible and easily identifiable markers of difference. Folk concepts about difference such as 'Asians' or 'White Europeans' involving grouping together people of similar skin tone were readily deployed, yet at the same time when I asked professionals questions about ethnicity (or ethnic minorities) they signalled their discomfort with such inquiries. With this realisation, in the latter half of fieldwork, I refrained from questioning professionals about 'ethnicity' and instead I asked professionals how they felt that service users' culture impacted on their work.

Managing (an)Other: intersections of culture, disability, and risk

Primarily, professionals involved in my research at Kotoka conceptualised culture as a property of the Other, and in these terms, it was only ethnic minorities who practised culture. In the UK, writers have recognised the inherent assumption that white people do not have culture (Jeyashingham, 2012) because culture has traditionally been

conflated with the exotic, on the one hand, or ‘as deficit’ (Park, 2005) on the other hand. The novel finding of my research, however, is that the conceptualisation of ‘culture as deficit’ was propagated by ethnic minority professionals in Kotoka. There was also an interesting contrast between the attitudes of two white women in the ST. Abby, manager of the ST, told me in interviews that her ethnicity was Afrikaans. Abby stressed that she considered herself an ethnic minority in the UK (although she was white). Abby displayed a reflective understanding of culture. She viewed culture as the ‘normal’ things that ethnic minority service users did in their daily lives: food eaten, music listened to, and religion. Furthermore, Abby perceived cultural practices as beneficial to service users. Abby felt strongly that issues about discrimination of the Other did not receive the attention required in the local authority and, as such, she had devised policies requiring the inclusion of BME advocates in MCA cases involving ethnic minorities:

[W]hat our policy does say is that someone can have an IMCA but they can also have another advocate. So for example there’s the National Equalities Council who or Equalities National Council, yeah, they do an odd way round; Equalities National Council, they provide advocates from there. [Their] speciality is dealing with cultural concerns [...] so they’re not IMCA’s [...] and they’re a charity as well so they’re neutral. (Taped interview, Abby, 12 July 2011).

In the quote above Abby is explaining that, in addition to statutory IMCA provision, service users could also access more ‘neutral’ advocates. She mistrusted the (im)partiality of the IMCA service available locally because it was commissioned by

the local authority (similarly Buchanan and Walmsley (2006) identified a potential conflict of interest from ‘closeness to power’ of advocacy groups funded by local authorities). Abby’s keenness to ensure independent advocacy for BME service users contrasted with her colleague, Emma, who felt that culture was a property of the Other. The context of the data extract from our interview, below, was that I asked what cultural issues would be considered in safeguarding work with ethnic minorities:

There’s no way that anyone can hope to become an expert in all the cultures represented within [the borough]. So what we have to do is be open-minded and know where to go for the information. (Taped interview with Emma, deputy safeguarding manager, 1 July 2011).

In the above statement Emma pointed to the apparent ethnic diversity of the borough as making it impossible for any professional to be ‘an expert in all cultures’. Emma could also be interpreted as implying a multiplicity of cultures in the borough and, in the face of difference; professionals could be absolved of their responsibility to know about different cultures. Consequently, the onus fell on the Other to provide information about the culture when sought by the professional. Emma thought that it was the less powerful in the borough – that is minorities – who had to form advocacy groups to provide information about their culture, whereas her colleague Abby took the opposite view.

Moving from the level of service provision to the conceptualisation of culture, professionals displayed varying understandings. A more sophisticated understanding was that of Adwoa, a Black British social worker of Ghanaian origin – ‘culture is a construct...maybe I am going too deep.’ Adwoa’s social constructionist stance on

culture was an exception. More commonly, professionals in Kotoka described culture as historic – ‘things that identify with their background’ – or a heritage that people wished to maintain. Even amongst the ethnic minority professionals (other than Abby), culture was always a property of the Other but there were variations on this theme. For instance, a professional would accept that in the UK they were a minority and, therefore, would describe themselves as Black British (Grenadian ancestry). Yet when they spoke about Grenadians living in Grenada, they positioned themselves as ‘outsiders’ and described people living there as ‘they’ instead of ‘we’ or ‘us’. By describing Grenadians vis-à-vis themselves as ‘they’, professionals in this sense were self-classifying as British simultaneously as they positioned themselves as minorities in the UK, given their blackness. This multiple positioning was evident even amongst the workers who were not UK citizens. For instance Mavis (American of Hispanic origin) said that her parents still spoke Spanish but talked about Guatamala as a faraway land – ‘in Guatamala they...’ although she visited the country of her parents’ birth regularly as a child.

Highlighting that minority professionals positioned BME service users as the Other is important because, in the social work literature, there is increasing stress on cultural competence. By cultural competence, it is meant that providing professionals with knowledge about a culture led them to treat service users with dignity or respect (Harrison and Turner, 2011). Another underpinning assumption of cultural competence was that minority professionals would better understand BME service users’ needs. The data I have presented above, suggesting that professionals positioned minority service users as the Other, undermines this assumption of the concept of cultural competence. In the next section I illustrate this further by presenting the life story of Abdullah.

Abdullah: culture as risk

The case of Abdullah (a Somali migrant) epitomised how positioning of BME service users as the Other and conceptualisation of ‘culture as deficit’, become enmeshed in care planning and risk management. Of particular interest in Abdullah’s case was that it involved Annika, who described herself to me as an Australian national with Nicaraguan roots (her family migrated to Australia when she was 7 years old). Annika became involved with Abdullah’s family following a referral from the Probation Service requesting that a social worker be present during the risk assessment of Abdullah’s brother Buba. Buba was due to be released from prison on licence for murder and professionals were assessing his family home as one of the places that he could live on licence. Preceding the referral from the Probation Service, Abdullah was awaiting a Core Assessment by professionals in Kotoka having just turned 18 and now classified as ‘adult’.

Being the first social worker from Kotoka to meet Abdullah, a visit billed initially as a risk assessment turned out to be a Comprehensive Assessment of him. Annika thought Abdullah to be ‘the most disabled’ service user she had ever met. On the face of it, however, Annika did not have cause for concern about Abdullah. Though he was diagnosed as having cerebral palsy, learning disability, had to be nourished through a gastro-peg, and could not exercise independent physical movement, Annika had learnt from professionals acquainted with the family that they provided exemplary care for Abdullah and that one of his sisters was a nurse. These ‘protective’ factors notwithstanding, Annika felt that Abdullah could be at risk because of his ethnicity. Interpreting Somali culture as ‘we look after our own’, Annika felt that the family’s heritage would prevent them from seeking statutory intervention.

Annika distrusted the family. During the risk assessment, Abdullah's father was present but Annika presumed polygamy and thought that he lived with another wife at a separate address. Furthermore, Annika speculated that the family were not using 'Direct Payments' (DP) allocation of 15 hours from children's services to pay for a carer and were instead supplementing their income with DP. Annika also felt that Abdullah's mother had to be 'educated' that care in the UK was formalised:

In the course of the discussion I asked Annika what she felt the cultural issues were and her answer was 'we look after our own.' Annika felt that she would need to let the family understand that they should welcome services and professional intervention. Annika said that Abdullah's sister needs to 'educate' [Annika's word] her mother about the formalisation of the system in the UK as her mother had the misconception that things were informal [...] Annika felt that this reluctance to welcome professional intervention stems from the family's culture...they believed that Abdullah would get better when this was not the case. Intriguingly, Annika based this assessment on the stigmatisation of disability in the culture of the 'Horn of Africa'...As disability is stigmatised, people have to believe that one would get better. (Field notes, shadowing Annika, 22 July 2011).

In the data extract above, Annika identified two cultural beliefs around disability in the 'Horn of Africa' where Somalia is located: firstly that it is stigmatised and secondly, people believed erroneously that disability could be cured. An undertone of Annika's distrust of the cultural belief that disability could be cured was that it flew in

the face of 'science' and medicine which both decreed the opposite. Also Annika's stereotyping of Somali culture as 'we look after our own' prevented her fathoming the possibility that some families did not want statutory intervention, especially in the case of Abdullah, whose care had been described as 'exemplary' by other professionals. Previous research has shown that professionals presume 'Asians' will seek to 'look after their own' (Mir and Tovey, 2002). However, the case of Abdullah shows that cultural stereotypes could also be the basis for intervening as the Other's way of living is assumed to pose risk.

Annika's views on risk discussed in the preceding section epitomise the view of 'culture as a deficit' held by professionals in Kotoka. That these views were expressed by professionals who themselves may be classified as BME, and who also maintained that their practice was underpinned by values, made the discussions uncomfortable for me, a black researcher. On a different note, the data I have explored here go to the heart of the conceptualisations of culture; that people take multiple positions on the subject on the basis of their own values.

Conclusion

Adopting safeguarding as an analytic standpoint, I have examined professional and institutional responses to risk in Kotoka. In Part One of this chapter, using evidence from the Comprehensive Assessment form, I showed that risk in Kotoka was 'observer-independent' (Searle, 2006), because the assessment and mitigation of risk was constructed as part of the job of social workers through various government and local authority guidance, and that this would be the case irrespective of subjective interpretations by professionals. This brought into sharp focus safeguarding, which was the broader policy framework for assessing and mitigating identified risk. At the

same time as considered 'real' in Kotoka, the policy framework of safeguarding nevertheless also epitomised the 'epistemic subjectivity' of risk. The data I have presented in this chapter show that professionals took divergent viewpoints on risk interpretation, or on how to heuristically apply their duties and powers (Searle, 1996). Thus while institutions matter to the discussions on policy, mainly, in this chapter; it is the role of powerful actors that I have shown. I evidenced how Martina, as chair of safeguarding meetings, used her knowledge of service users to categorise cases, especially when solutions to service users' 'complex' problems were not readily identifiable. Thus in the assignment of risk categories powerful actors (such as team managers) can override the views of service users.

Another issue that this chapter has shown is the methodological and substantive difficulty of operationalising social categories in applied research. Starting with ethnicity, professionals appeared reluctant to discuss the topic for various reasons. One important reason may be, however, that in everyday language other equally complex concepts could operate as proxies for the concept of ethnicity - examples include BME, culture, and minority. But while in everyday interactions there is a common or shared understanding of these three latterly cited concepts, arguably, they lack the sense of wholeness researchers aim to convey when they deploy the concept 'ethnicity'. This may also be said of learning disability or mental capacity: both concepts tell us something at the same time as leaving us with an imprecise picture of the people being described. As a result, a strong case can be made that, when studying social categories, there will be disjuncture between the researcher and research participants' understandings of the issue at hand. In the case of my fieldwork, for instance, this latter point was evidenced by how often professionals shifted their ethnic identities. Arguably, therefore, paradigmatically,

there is the need for qualitative research whereby researchers attempt to gain a fuller understanding of people's interpretation of social categories, noting what they say and/or do about phenomena. There is also the need to research the lives of people who embody social categories to understand how they shape and are affected by these statutory categories. In the next chapter, I address the issues outlined in this paragraph by presenting the case study of Abrax.

CHAPTER SEVEN. ABRAX: LIVING WITH SOCIAL CATEGORIES

This chapter (re)presents my case study of Abrax who was simultaneously classified as learning disabled and an ethnic minority by professionals. Because of Abrax's status as learning disabled, he was concomitantly a person falling within the remit of the MCA. During fieldwork I modified my ethnographic methodology to incorporate a case study to gain breadth and depth of the substantive concerns of my thesis. Although in lived experience the past, present, and future interplay (Adam, 2010), by necessity this chapter is thematically organised around childhood and adulthood. This is because in statutory services the label learning disability is acquired during childhood (DOH, 2001) while a person's capacity to make decisions is formalised in adulthood. Therefore in Part One, under the theme of childhood, I draw predominantly on life story interviews with Abrax's parents to identify three key incidents in his infancy which still resonated in his life or in the narratives told about him in adulthood. The three incidents were (a) Abrax acquiring the label of learning disability (b) the first time Abrax was given a wheel-chair at the age of ten (c) and finally, his time at Marigold (an SEN school). In Part Two, I discuss Abrax's life in his supported accommodation, Yarlow, based on observations, interviews, and documentary analyses.

Abrax: painting a portrait

Abrax, a 19-year old man of Greek-Cypriot origin, was classified as learning disabled. At the time of fieldwork, Abrax required care at all times to meet his physical needs. He was assisted with 'personal care' such as using the bathroom, washing, dressing,

and eating. Abrax could not control his muscles; consequently, he was not able to keep his torso upright or stand unaided. Therefore, Abrax wore a vest prescribed by a doctor to keep his torso straight-up (his carers called the vest ‘bodysuit’) and he used a wheelchair permanently. Due to these requirements, Abrax was classified as needing 24-hour one-to-one support provided as part of his tenancy in a newly converted supported living accommodation, Yarlow. The house was owned by a private company (hereafter referred to as care provider) which was contracted by the local authority to provide day care and accommodation services. Adjacent to another learning disability-licensed accommodation owned by the same company, Abrax’s home was authorised to accommodate five service users. However, at the time of fieldwork, Abrax lived with two flatmates Alexander and Naomi. Noticeably, unlike the other tenants in both houses, Abrax was supported by a designated team of five men who co-incidentally were all Black Africans. During my field work I was regularly told by both female and male carers that Abrax insisted on being supported by male carers because he was mindful of his privacy, however I found no evidence of when and how Abrax communicated this wish.

Key to communicating with Abrax was other people’s willingness to recognise his ability to make his views known. Abrax had a unique way of communicating: he did not construct sentences and he only vocalised single syllable words. As such, to communicate with him, one used closed questions - for example ‘should we go to the cinema?’ In response to closed questions Abrax made sounds, which the listener interpreted as either ‘yes’ or ‘no’. If the person was uncertain, they asked Abrax a follow-up question – ‘is that what you mean?’ Generally Abrax’s carers talked to him as if he would respond verbally (although he did not) and they told him about future events. I heard Abrax addressed in the third person along these lines: ‘And then Abrax

will have his cup of tea and then when he finishes that he would go out for the day...’ Abrax’s carers, in addition, anticipated certain situations where they believed he would like to exercise choice, and asked him ‘yes and no’ questions to which he gestured or vocalised his responses.

Occasionally Abrax’s responses were not decipherable or he responded ‘yes’ or ‘no’ to the same question in a different format or tone, which led his carers to run through a list of possibilities. Furthermore, Abrax’s use of single syllables suggested a limited vocabulary (for instance when he was asked my name he would say ‘ta’ after being told that I am ‘Godfred’); however he expressed strong views through loud, continuous noises if his wishes were not acceded to. Even so, Abrax required his carers to decipher whether the noise was an expression of displeasure or happiness. All these issues made it seem as if communication with Abrax was, to some extent, informed by inferences from Abrax’s previous choices, his family history, and his demonstration of his strength of feeling on a matter. Predominantly people within Abrax’s social network believed that they could understand his sounds.

At the time of fieldwork, Abrax’s social network encompassed his family, his care provider, Kotoka (local integrated learning disability social services) and his old school Marigold. These aforementioned institutions were important to Abrax because their actions resonated in his life. When I met Abrax, he had known the care provider for less than six months, but in that period, the service had assumed centrality in his life. In addition to accommodation, through his five male carers at Yarlow, the care provider planned Abrax’s life: Abrax attended day services on separate company-owned premises; he visited social clubs in the evenings; and he had frequent contact with his parents. In contrast to Abrax’s regular contact with the care provider, he had little engagement with Kotoka, although it funded his services. Similarly, Abrax had

little contact with Marigold where he was a pupil between the ages of 4 and 19 but Marigold resonated in Abrax's life. For instance, Abrax still attended his annual physiotherapy sessions in Marigold and a few school staff visited him at Yarlow. It was also at Marigold that Abrax's birth name was replaced by staff so that at the time that I met him, he was routinely called Eric, even by his parents.

The final notable feature of Abrax's social relations was his family: his parents Mr and Mrs Chantos, his brother and sister, his maternal grandparents, his uncles, aunties and their children. Abrax's family had a strong sense of its Greek-Cypriot origin. Although both of his parents were born in the UK, they observed Greek-Cypriot traditions, which according to them included: closeness to family, celebrating the birthday of the patron saint one was named after, and going to church. At home Abrax's parents and siblings spoke English, but Abrax's grandparents spoke little English. Abrax's parents described the language their respective parents spoke as 'Greeklish' – implying a mixture of Greek and English. Mr and Mrs Chantos said that as a result Abrax understood Greek because that's how his grandparents communicated with him. Abrax's dual heritage as Greek-Cypriot and British, therefore, epitomised the current consensus that ethnic (self)categories are variable and contextual (Nayak, 2005).

Part One. 'Critical moments' in Abrax's childhood

My discussions here are influenced by the concept of 'critical moments' defined as 'an event described in an interview [or research data] that either the researcher or the interviewee sees as having important consequences for their lives and identities' (Thomson et al, 2002; p339). The 'critical moments' concept was developed by

Thomson et al (2002, 2005) from their longitudinal study of how the choices young people and/or their families make within their prevailing socio-economic circumstances impact on their future lives. Elsewhere the writers have emphasised that ‘critical moments’ are extrapolated from the narratives told by people or by others about them within the research context (Holland and Thomson, 2009). Based on the latter theorisation, I commence Part One with an account of how Abrax became categorised as learning disabled. I subsequently show that, although Abrax’s parents exercised some agency in his acquiring this label, they resisted its full connotations by delaying Abrax’s use of the wheel-chair. Another form of resistance was that Abrax’s parents sometimes refused to ‘accept’ that he was not capable of deciding for himself. In the last section of Part One, I discuss Abrax’s time at school and how narratives developed about his character resonated through to adulthood.

Acquiring ‘learning disability’

Mr and Mrs Chantos told me in an interview, tape-recorded at their house, that Abrax was born after a ‘normal’ 40-week gestation period. Aged six months, Mr and Mrs Chantos noticed that Abrax did not exhibit capabilities similar to their friends’ children. In the data extract below from one of the research interviews, Mr and Mrs Chantos explained the physical signs that initially alerted them to seek medical advice about Abrax’s development:

Data extract 1

Godfred: I was hoping that you could tell me like about him, and, like as much as you can from when he was born until [...] but obviously tell me what you want to tell me.

Mrs Chantos: He was born normal birth, [...] we started noticing there was something wrong with him at six months when he wasn't doing what he was supposed to do: hold his head up, smile, do things that six months babies should be doing and that's when they started to investigate... hospital after hospital [...] yeah, he wasn't holding his head, I mean he could lift his head but it was like, lift it.

Mr Chantos: It was quite floppy.

Mrs Chantos: And then it would drop again. He wasn't able to hold it and sort of look at you and just be strong.

Mr Chantos: We had concerns so we went to the...I'm not sure we went to the GP initially or [Mrs Chantos: health visitor] and we said 'look, we think this is not right. We were expecting him to be doing this' and we had friends that had kids around the time, didn't we? So there was an easy comparison. Plus as parents we noticed as well didn't we? And they should be doing a little bit more at that age (Taped interview, Mr and Mrs Chantos, 26 November 2011).

In data extract 1 above, Mr and Mrs Chantos explained that they sought advice from their GP after noticing that at six months of age, Abrax was still 'floppy.' Unable to explain Abrax's physical condition, the GP referred him to Great Ormond Street Hospital (GOSH) (Abrax remained under the care of GOSH until the age of 16.) Later

on in the same interview (data extract 2) Mrs Chantos said that in an attempt to diagnose Abrax, doctors at GOSH conducted several tests to ascertain his level of understanding:

Data extract 2

[I]t was just test after test, ability test just to see how his mind works, and see if he can understand what they're saying, and what they're not saying and if I'm not mistaken, they gave him, I think he was 8 or 9 at the time and they said that from what they can understand his ability was for a child that was probably three or four years younger than him (Taped interview, Mrs Chantos, 26 November 2011).

In data extract 2 above, Mrs Chantos explained that doctors at GOSH diagnosed Abrax's mental abilities as lower than his chronological age (but Mrs Chantos also said in the same interview that Abrax's mental capacity confounded all expectations). It is, however, worth comparing data extracts 1 and 2 because whereas in the former it was a physical issue – 'he wasn't holding his head up' – that initially prompted Abrax's parents' 'concerns', subsequently in 2, medical examinations became focused on his mind. In extract 1, Mr and Mrs Chantos referred to Abrax being 'floppy' at 6 months, but in 2 Mrs Chantos explained that by the age of 8 or 9, tests centred on 'if he [Abrax] can understand what they're saying'. Notwithstanding frequent examinations, Abrax's condition was not diagnosed at GOSH as, according to Mrs Chantos in the same interview, 'there wasn't a diagnosis; they haven't actually said what's wrong with him' (taped interview, Mrs Chantos, 26 November 2011).

Interpreting Mrs Chantos' quotations above, Abrax did not acquire the label learning disabled through the health system.

Abrax's categorisation as learning disabled occurred within the education system. At the age of three, his parents were advised by a health visitor to send him to a private nursery with a reputation for helping disabled children. Nursery staff subsequently advised Mr and Mrs Chantos to seek a Statement of Special Educational Needs (SEN) for Abrax so that their local authority would fund his place. Accordingly it was through SEN that Abrax acquired the label 'learning disability'. Abrax's categorisation as learning disabled, therefore, reflects the materialist orientation of the social model, wherein it is said that the label 'disability' is acquired as people attempt to access resources or social spaces (Gabel and Peters, 2004). In the case of Abrax, his parents aimed to access education that they felt would meet his needs. Through the SEN assessment, Abrax became known to Marigold.

Abrax's life story draws attention to the education system: firstly, as an institutional context for classifying certain social presentations as indicators of learning disability, and secondly, for identifying and fitting individuals into learning disability categories (Gerber, 2007; Keogh, 2005). More broadly, Abrax's life story demonstrates that classification by state institutions potentially resonates through the life course. Once categorised as learning disabled and 'Statemented', Abrax would become subject to regular statutory assessments which culminated in his being given supported living accommodation just before I met him. Marigold was an important aspect of Abrax's life. Apart from education, it would seem that a narrative about Abrax as a person and character was co-constructed by Marigold staff and Abrax's parents.

The story so far throws into sharp focus the interplay of structure and agency through which social categories become embodied. Abrax's entry into a key social structure – the education system – led to his classification as learning disabled. Although Abrax's categorisation as learning disabled may be seen as structure impacting on lived experiences, Abrax's parents told me that they wanted him classified so that he could access private nursery education. Thus it may also be concluded that Abrax was classified learning disabled through his parents exercising their agency. But simultaneously, as they played agential roles in Abrax's categorisation, Mr and Mrs Chantos resisted the accompanying material and spatial (re)configurations associated with learning disability.

Resisting categories: objects and narratives of (in)dependence

Mr and Mrs Chantos associated key developments in Abrax's life with material and spatial changes. Aged 10, Abrax first received a wheel-chair, which according to his parents changed their lives because until then, Abrax relied on others to take him from place to place. Before obtaining the wheel-chair, Abrax also watched his siblings running and moving without being able to do the same. However, being given a wheel-chair increased his awareness of his physical and mental capacities to move through spaces independently. On Mr and Mrs Chantos' part, Abrax using a wheel-chair made them see him in a different light, as a person capable of making decisions about which part of their house he wanted to explore without his parents' consent. To illustrate further the theme of space and capacity in this section, I introduce below some interview exchanges between myself and Mr and Mrs Chantos.

Godfred: [Tell me] like really key things that stick out for you in Abrax's life and for him.

Mr Chantos: You know the fact that he ended up having a wheel-chair – we knew it was gonna happen.

Mrs Chantos: Yeah.

Mr Chantos: But making that decision to have a wheel-chair, I think that was, I think that was a milestone.

Mrs Chantos: Yeah.

Mr Chantos: Because he was getting older, we could, we couldn't use the pram to wheel him round here, you needed to move the next step up, and I think that was a milestone, definitely! Cos then, its saying 'yes, you have acknowledged that he is disabled' or he is; but I think that was a milestone in our head; it was; it gave him the freedom.

Mrs Chantos: His freedom, wasn't; it gave him the freedom to move around the house.

Mr Chantos: Cos he took to the wheel-chair.

Mrs Chantos: Like duck to water.

Mr Chantos: Yeah (Taped interview, Mr and Mrs Chantos, 26 November 2011).

In the interview exchanges reproduced above, Mr and Mrs Chantos explain the symbolic value of Abrax acquiring a wheel-chair. For Mr and Mrs Chantos the wheel-chair was the point at which they ‘acknowledged’ the medical prognosis that Abrax would not be able to walk unaided. Up to then they resisted the full implication of ‘disability’ by delaying Abrax’s use of the wheel-chair even though they were told about its inevitability – ‘you know the fact that he ended up having a wheel-chair – we knew it was gonna happen’. Their leaving the decision about the wheel-chair for as long as possible suggests a deliberate strategy on their part to defy medical prognosis.

It is also instructive that, before he was given the wheel-chair, Abrax’s parents put him in a pram, a device which is used to mobilise babies and toddlers. Thus, the pram and wheel-chair powerfully illustrate how material objects link into key life transitions, and their emotional impact on people. On the basis of the freedom that Abrax demonstrated on getting his wheel-chair – ‘it gave him freedom to move around the house’ – the wheel-chair may be said to be the point at which he separated from his parents, from being a child to becoming a teenager, when Abrax was given the opportunity to demonstrate both physical and mental abilities previously unrecognised by his parents. Where beforehand he needed his parents’ consent before being wheeled in the pram to new locations, with the wheel-chair Abrax could demonstrate to other people his mental capacity to think through his spatial positioning, and secondly, enact his will to get to that location. For Mr and Mrs

Chantos, on the other hand, the wheel-chair had an emotional impact because it was the point at which they yielded to the 'inevitable' medical advice that Abrax would need additional aids for his mobility.

Another interesting revelation from my interviews with Mr and Mrs Chantos was that they moved between descriptions of Abrax as having 'disabilities' or 'abilities'. One way that Mr and Mrs Chantos reconciled the conceptual space between 'disabilities' and 'abilities' was through the use of narratives about Abrax's personal character and his high levels of cognitive capacity, which they believed, defied the full connotations of learning disability. To further elucidate these latter points, I now introduce some interview data in which Mr and Mrs Chantos described Abrax's time at Marigold. It was during his time at school between the ages of 4 and 19 years old that the institutional and personal significance of the label learning disability was realised, thus making the school an important domain of Abrax's life. In my interviews with Mr and Mrs Chantos, their narration of Abrax's Marigold experiences was one of a 'popular' student who 'loved' going to school, and who over-achieved academically in spite of his 'disability':

Data extract 3

Godfred: How would you describe Abrax going through Marigold, how would you describe his experiences from Marigold?

Mrs Chantos: He loved it [...] towards the end of his school years he didn't want to come home [...] He was waiting by the door for the bus to come and get him [in the mornings]. He loved it at school because he

became so popular with everybody, everybody knew who he was, all the teachers loved him, he loved everyone, you know, it was just...

Mr Chantos: He's just popular...he's so popular isn't he?

Mrs Chantos: And the learning aspect, they did say to me that you know he's doing well! He was, considering the abilities that he's got and his disabilities, he was doing well at school. (Taped interview, Mr and Mrs Chantos, 26 November 2011).

The above data extract shows movements between the past and the present, coupled with a slide in and out of acceptance of Abrax's categorisation as 'disabled' on the part of Mrs Chantos. Mrs Chantos talked in the past tense – 'he didn't want to come home'; 'he loved it at school' but her husband on the other hand spoke of the present – 'he is so popular'. The overlapping uses of past and present tenses by each parent demonstrated that the narratives developed about Abrax's personality in childhood still resonated with both parents. Specifically with Mrs Chantos, in the last sentence she talked in the present to affirm Abrax's apparent disability ('and his disabilities') simultaneously as she confirmed his abilities ('considering the abilities that he's got'), and then moved on to characterise Abrax's time at school as successful ('he was doing well at school!').

Mrs Chantos 'accepted' in the last sentence that Abrax was not able to perform certain actions, or that he was disabled in some respects. However, in his everyday life, Abrax displayed abilities which defied the essence of the term learning

disability. For instance, Abrax's parents observed that he had a good memory, as Mrs Chantos explained later in the interview:

Like I'd say to him today 'next week its baba's [your father's] birthday'. During the week I would say, 'whose birthday is it this week?' [He would answer] 'Baba'. Things like that, you know, that's when we realised 'well hold on a minute, you know, he's got a very good memory'. (Taped interview, Mr Chantos, 26 November 2011).

Since a good memory is not usually associated with learning disability (or mental capacity), in the last sentence of data extract 4 above, Mrs Chantos pulled back from the full implication of her acknowledgement of Abrax's disability. Instead she qualified that Abrax performed better than implied by his SEN category.

The discussion to date about how Mr and Mrs Chantos simultaneously resisted and welcomed the education system's categorisation of Abrax shows that, in their everyday lives, people can display more capacities than conceptual classifications capture. Furthermore, the interview data I have presented in this section show that Abrax was regarded by his parents as contesting social categories through the personal character he displayed; for example, his adjudged sociability, even temperedness, and memory. Mr and Mrs Chantos, on the other hand, moved between acknowledging and resisting learning disability, sometimes through the narratives they deployed about Abrax. In the next section, I discuss one narrative that both Abrax and his family appeared to accept unconditionally – his unofficial name Eric – which was constructed by staff at Marigold.

Marigold: becoming Eric and transitioning to Yarlow

‘Eric’ still resonated in Abrax’s life when I met him because he was routinely called by that name. Indeed, after my first visit to Yarlow, I left with the impression that Eric was his official name. When I realised Abrax’s name, I formed a hypothesis that the point at which he became Eric was a ‘critical moment’ because peoples’ names were part of their cultural identity. I therefore focused on understanding the circumstances that led to Abrax becoming Eric. One day I accompanied Abrax and his care worker Robert to Marigold for a physiotherapy session. On this visit to Marigold, I met Dominic (Abrax’s old teacher) and took the opportunity to ask about the origin of ‘Eric’. Below are the extracts of the field notes I recorded from my exchanges with Dominic on the subject:

Throughout fieldwork I have been intrigued by how Abrax came to be known as Eric. On this trip to the school I took the opportunity of meeting Abrax’s old class teacher Dominic to ask where the name came from. Dominic said that he did not know for sure but he thought that Abrax was given the name after he was called Eric by one of the students and he appeared to like it. Dominic said that as his parents did not seem to mind him being called Eric, it has now become his de facto name. (Field notes, 3 February 2012).

In the data extract above, the ‘critical moment’ in Abrax’s life (Thomson et al, 2002) could be identified as the point where a member of staff reported that he liked being called Eric. Inherent within the name Eric is also an informal assessment of Abrax’s mental capacity. For the member of staff to accept that Abrax liked the new name,

Eric, they needed to believe that Abrax had the mental capacity to process such information: Abrax heard the sound, interpreted it as a name being given to him, and lastly, demonstrated to an audience that he liked being called Eric. Situating the past, as recounted by Dominic, into the period of my fieldwork at Yarlow, I witnessed Abrax refer to himself as Eric. An illustrative account from my field notes (presented below) is when I accompanied Abrax cycling and he was asked his name by the attendant Ken. Ken, however, believed that Abrax could not tell his name, judging from his physical appearance and his monosyllabic communication on our arrival. Based on this stigmatisation of Abrax, Ken addressed his question to Anthony (support worker) and me but, as indicated below from the field notes, Abrax responded to the question from Ken:

I saw Ken ask ‘what’s his name’ and Abrax said ‘Er’ which I took to mean Eric. I felt that this was significant because: firstly, that Abrax understood the question; that Ken addressed the question to Anthony, and [...] when Abrax said that his name was Eric, Anthony told Ken that his name was Abrax. (Field notes, 07 December 2011).

The preceding data extract can be read as Abrax displaying an understanding of his personal identity. More specifically, Abrax evidenced an understanding of his unofficial name Eric. On this occasion, however, his support worker Anthony corrected Ken, telling him Abrax’s official name. While showing that Abrax understood questions about his subjectivity, another interpretation of the data could be that he had internalised ‘Eric’ as his own. A feasible interpretation of the preceding data extract therefore is that Abrax liked being Eric and wanted to be called so. Thus, arguably, by adulthood Abrax accepted that he had become Eric. The fact that

Abrax's parents not only agreed to Eric but called him so in my latter conversations with them shows how much of the school's narrative about Abrax was acceptable to Mr and Mrs Chantos. Alternatively Mr and Mrs Chantos felt that the school's narrative was so powerful that they could not resist the name 'Eric'.

From the perspective of ethnic identity, it is instructive that 'Eric' was arguably a more British (or English) name than Abrax. On the part of Mr and Mrs Chantos, accepting their child being renamed Eric would have been unproblematic given that they saw themselves and Abrax as having a dual Greek-Cypriot/British heritage. Thus attention focuses on the intention of the person who first proposed the name – whether they sought to impact 'Britishness' to Abrax.

I end this section about critical moments in Abrax's childhood by highlighting that, in my interviews with Abrax's parents and his carers, it was agreed that staff from Marigold played a significant part in his living at Yarlow. For instance, in my field notes from a separate visit to Mr and Mrs Chantos on 17 November 2011, I wrote that they recounted how their interest in supported living originated from advice by staff at Marigold:

In the discussion I recall inquiring about how Abrax came to move to Yarlow. His parents said that it was staff at the school who told them that they thought that Abrax could live in 'supported accommodation' (their words) [...] Abrax's parents said that when they were told this [about Yarlow] by the school they requested it from social services (Kotoka). Interestingly they did not remember that the Integrated Team are based at [address withheld] so this perhaps exemplifies their distance from statutory [social] services. (Field notes, 17 November 2011).

In the above data extract, Mr and Mrs Chantos are recorded as implying that the statutory work around Abrax's transition to adulthood was conducted by school staff instead of social workers, as is usually the case in disabled children's services. The data extract above also exemplifies the narratives of trust which Mr and Mrs Chantos employed when they talked about school staff. It was through the advice of Marigold staff that Abrax first became known to the local children's services and Abrax's parents employed professionals from Marigold using Direct Payments. There was, therefore, a strong bond between Mr and Mrs Chantos and Marigold as an institution. With respect to the MCA, accompanying guidance advises that mental capacity assessments be conducted during accommodation changes (Harker, 2012). However, neither Abrax's parents nor professionals at Yarlow recalled a capacity assessment being conducted before he moved to Yarlow, although the MCA had been implemented by that time.

My analytic discussion so far has shown that 'critical moments' (Thomson et al, 2002) is a useful conceptual tool to identify key incidents in the story people told me about Abrax's life which resonated into his adulthood. As a baby, Abrax's parents had 'concerns' because he was 'floppy', leading to his being classified as learning disabled through the education system. I posited in my accounts that Abrax's classification draws attention to the binary nature of disability categories, especially in relation to service provision. Although Abrax required a wheel-chair as well as physical support, it was his mind that became the focus of categorisation. That Abrax was classified as learning disabled mattered because it led to his being assigned to a SEN school, Marigold, where he was given a new name Eric. It was also at Marigold that narratives about Abrax as 'popular', 'able', 'high achieving' with a 'good

memory’ developed. In a different less empowering environment than Marigold, Abrax’s life might have been different. By the time I met Abrax, it was a well-established part of his life story that he could make his own decisions. Moving now into Abrax’s adulthood when I became acquainted with him, in the following section, I discuss how the notion that Abrax could make his own decisions was operationalised at Yarlow.

Part Two. Abrax: recognising his mental capacity

Framed around my explorations of narratives told about Abrax’s mental capacity to make decisions, in Part Two, I address my observations of Abrax’s life in Yarlow. I have themed the first half of Part Two ‘Recognising Abrax’s Mental Capacity’ to show how daily interaction with Abrax started from the premise that he could make decisions for himself. To contextualise the forthcoming discussion, I now provide an overview of Abrax’s care in Yarlow. Abrax moved to Yarlow in August 2011. When I first met Abrax, he was supported by four men - Anthony, Robert, Helder, and Abassi - who all described themselves to me as Black Africans. This four-person team worked on rotation throughout the day: a morning shift was 8AM – 3PM, an afternoon shift lasted between 3PM and 10PM, while a night shift ran from 10PM until 8AM. At the beginning of fieldwork Abrax lived with Alexander (also of Greek-Cypriot heritage) and they were both joined by Naomi towards the end of my fieldwork. Abrax’s dependence on other people’s physicality meant that, in his life, mental capacity extended beyond cognition to issues of physical (in)dependence. Although decision-making in Abrax’s life at Yarlow followed a relational model, formal records of Abrax’s care painted an individualistic picture of his decision-

making. Through the use of the first person 'I', Abrax's carers (mis)represented his mental capacity in documents called the Learning Log. I expand further the theme of documentation in the next section.

Staff recordings of Abrax's mental capacity

In their work with Abrax, his team of four men were required to formally record their shift activities. Such documentations were made at the end of each shift, in addition to verbal exchanges of information. The handover points of staff were, therefore, an important aspect of their work with Abrax because they were key moments in planning for his life: staff talked about the activities that Abrax engaged in during the day, significant events that could impact on the next shift, and changeover staff received suggestions about what they could do with Abrax. The Learning Log, however, was viewed by managers as written evidence of Abrax's routine. During fieldwork I was allowed to photocopy about two months' worth of entries in the hardcopy of the Log, which I have analysed together with interview transcripts and field notes. It is interesting to note that nearly all the Learning Log entries were completed in the first person 'I' - in Abrax's voice - as if he had solely made the entries. Noticeably, whereas Abrax's official name was usually written at the top of the Log, in the free-text section he was frequently referred to as Eric, thereby highlighting that his time at Marigold still resonated in his life in practical ways at Yarlow. The entry that I have shown below was written by one of Abrax's care workers, Helder, (date unspecified although the 18/10/11 was written and struck through), and in it he described his visit with Abrax to a Further Education (FE) college to seek Abrax's enrolment.

LEARNING LOG

Name: Abrax

Date	Who was Supporting me?	Summary of activities through the day	What worked well for me	What did not work well with the Activity
18/10/11 Open document please	Helder	I and Eric decided to follow up the appointment at Lola college that we initiated in 16/10/2011 [...] we called again Stephanie the course director [...] we then went for a walk in the local community to get to know people around my area [...] when I came back home, I and Helder called Stephanie again [...]	The news of me starting college made me very happy and I'm looking forward to it	

The entry which I have reproduced above is a microcosm of how Abrax's mental capacity was depicted by his care-workers in the Learning Log. By using the first-

person 'I' and writing in Abrax's voice, his care-workers implied that all the decisions were made by Abrax. The above extract from the Learning Log, for instance, could also be interpreted as: Abrax was recounting his decision to go for a walk without any prompting, or that Abrax was explaining his happiness at the possibility of starting college. Thus on paper, the written record created an Abrax who made his own decisions: the role of the support workers centred on helping Abrax enact his choices. There is, however, an interesting move between the third and the first person, exemplified in the column titled 'Summary of activities during the day' in which Helder began in his own voice 'I and Eric' until 'my' and 'I' in which Helder reverted to the voice of Abrax. Also, under 'What worked well for me', Helder adopted the first person 'me' to symbolise Abrax's voice. The reproduced Log, above, reflects the overall tone of the entries. Staff generally wrote in the first person but sometimes they started in the third person and shifted into using 'I'.

Noticeably, the columns of the Learning Log invited authors to use 'I'. As Abrax lived in supported living accommodation, the narratives around service provision included 'independence' and 'normality' (DOH, 2002); therefore training and company policy could explain the use of 'I' in the Learning Log. Staff espoused the view that supported living was better than residential accommodation because tenants chose their daily activities in contrast to the service-led approach in residential accommodation. Consequently, Abrax had to be depicted as choosing instead of merely being a recipient of services on offer. The more experienced staff were aware of policy and procedure requirements in Yarlow and, therefore, completed the Learning Log using 'I', a voice that depicted Abrax as in control. That training and experience influenced voice in completion of the Learning Log was illustrated by

Abbassi's entries who consistently wrote in the third person, an example being his entry on 8 September 2011:

When staff came on Eric was already smartly dressed @ 10:15am, his mum called to inform that she was coming and would like to see Eric before he goes out.

The above data extract reads that Abbassi wrote in a markedly different voice than Helder, when he described his visit to the Further Education College with Abrax. Helder was a more experienced care worker than Abbassi, as such their different usage of voice suggests that with further training, staff learnt to write in the first person to symbolise the mental capacity of a service user to make decisions about their daily routine. In this way staff constructed Abrax's mental capacity in official documents. However, it would be inaccurate to characterise the documents as fabrications because I witnessed some of the events described in the Learning Logs. For instance, Abbassi's entry, cited above, corresponded to my observation that Mrs Chantos (and the rest of the family) telephoned and visited Abrax frequently at Yarlow. Also I am mentioned in the Log entry on 10 October 2011: 'Godfrey Open University Researcher to involve Eric in research'. Therefore, while it may be said that through 'I' Abrax's care workers constructed his mental capacity the events logged were not mere inventions because I witnessed some of them.

The depictions of Abrax and the use of 'I' are so powerful that they invite a contextualisation of the Learning Logs within the broader debates about mental capacity research methodology. In the psychiatry literature, ethnographic work has shown that the symptoms depicted about patients on paper sometimes differed from

the narrative accounts of their conditions they provided to psychiatrists. As Barrett (1996) evidenced from his long-term anthropological work of a psychiatric hospital, textual accounts were usually formulated by professionals out of patients' accounts in order to fit predefined psychiatric categories. Moreover, textual accounts serve a particular function within organisations: 'written records are permanent, more highly institutionally regulated and constitute sites of demonstration of professional expertise, competence and accountability' (Georgaca, 2013). Based on Barrett and Georgaca's works cited it may be argued that it was not that Abrax's carers sought to deceive through their entries in the Log; rather, they made their inscriptions bearing in mind organisational expectations to 'empower' Abrax accomplish certain tasks. Thus for researchers to grasp the complexities of people's mental capacity, multiple accounts from documents, observations, and interviews have to be analysed to attain a more rounded picture of service users' (dis)abilities. In my fieldwork, on the substantive issue of mental capacity, I witnessed more complex interactions between Abrax and his carers than depicted in the Learning Log.

'Come and make a cup of tea': a relational approach to decision-making

Contrasting the individualised accounts of Abrax's decision-making depicted in the Learning Log, Abrax's carers told me that in their interactions with him, they started from the position that he could understand and make choices, and they frequently facilitated his decision-making by involving him in actions even when they knew that he lacked the physical capacity to enact his will. As further illustration, I now present data here from my field notes written after I shadowed Abrax on 18 October 2011. So that I can adequately contextual the data extract, it is necessary to provide a brief overview. I arrived at Yarlow around 8:05AM and I was let in by Natalie (support

worker assigned to Abrax's flatmate Alexander). Natalie said that Abrax was having his personal care. As I waited for Abrax, and we spoke about why I was shadowing him, Natalie said 'Abrax can make a lot of decisions but he [Alexander] can't'. (Field notes, 18 October 2011). The statement cited here shows that Yarlow professionals recognised Abrax's capacity: they believed and expressed the view that Abrax could make decisions about his care. Not long after, Abrax came into the room in his wheel-chair pushed by Robert. Robert said that Abrax would make a cup of tea so he walked ahead into the kitchen from where he urged Abrax to join him. In response, Abrax wheeled himself independently, an interaction that I captured in my field notes below:

He [Robert] was in the kitchen when he told Abrax to 'come and make a cup of tea' and I noticed Abrax respond by turning himself around in his wheel-chair and heading towards the kitchen. He then went towards the kettle and manoeuvred himself in such a way that the kettle was on the wooden [kitchen work] surface to his left. I recall that by this time Robert had filled the kettle with water and Abrax was to press the button on the kettle for it to start boiling. (Field notes, 18 October 2011).

In the data extract above, Robert encouraged Abrax to make a cup of tea. He recognised Abrax's capacity to understand verbal communication and drew him into part-making the drink. Robert was aware that Abrax did not fully control his physical body nevertheless he eschewed the easier option of simply making the cup of tea for Abrax. Instead he opened up two avenues through which Abrax could demonstrate his capabilities. Firstly, he spoke to Abrax as if the making of tea was a joint-action. Secondly, Robert offered Abrax the opportunity to demonstrate his physical

capabilities by encouraging him to start the kettle. Robert here may be said to be initiating the interaction from the premise that Abrax was capable of contributing.

Similarly when it came to Abrax eating his breakfast, it was from a starting point that Abrax was able to choose. Firstly, Abrax was asked for his choice, and then the food was placed in front of him whereupon he was allowed the time and space to eat:

I noticed that Robert would usually pick something out [of the cupboard] and say along the lines of ‘oh look at X, do you want some?’ and then Abrax would make a sound which would be interpreted by Robert as either affirming or disaffirming his question. When Abrax sat around the table to have breakfast, he had porridge and croissant. Robert cut the croissant up into pieces and encouraged Abrax to eat them. I noticed that Abrax responded to this. He stooped with his head very close to touching the table. He stooped so low that I thought that he would be picking the croissant with his mouth from the plate but then he used his left hand to pick the croissant and then slowly bring it to his mouth at which point he returned to an upright position. (Field notes, 18 October 2011).

The two data extracts I have presented show that, firstly, Abrax understood verbal communications directed at him because he responded to Robert’s call from the kitchen, the injunction to press the kettle switch, and finally to eat. Concomitantly, the two data extracts show how rich personal relationships fostered decision-making in Abrax’s life. Robert’s interaction with Abrax recorded above is symptomatic of how his care team related to him: they spoke to him on the assumption that he fully

understood, and they involved him in activities that they knew he could not fully engage in because of his physical dependence. But Abrax's reliance on his carers' physicality to enact his will was sometimes deployed by them to make him engage in actions to which he was opposed. For instance his carers knew that Abrax enjoyed daily bus rides and therefore used this as bargaining points. One day I accompanied Abbassi and Abrax to the day centre during which I made some field notes about how Abrax was encouraged to do something he initially refused to:

Abbassi offered him a yoghurt which he declined but by this time he had been saying 'bus' repeatedly which Abbassi thought meant that Abrax wanted to go on a bus ride. So when Abrax refused the yoghurt Abbassi told him that he should eat it first and then they would go for the bus ride. I recall that after this exchange I wondered whether Abrax's dependency on the carers to meet his physical needs meant that decision-making between them was a form of bargaining: 'if you do this then you can have this.' (Field notes, 4 November 2011).

The data extract above is one illustration of the numerous times that Abrax was 'convinced' to do things against his will. A commonality of these instances was that his carers felt that, based on their understanding of his needs, they knew what was best for him. In this way, their actions may be said to accord to the 'best interest' principle of the MCA: 'So sometimes it may be necessary to choose an option *that is not the least restrictive alternative if that option is in the person's best interests.*' (MCA Code of Practice, 2007; p27; emphasis added). For instance, I was told by Robert that when Abrax first moved into Yarlow, he was extremely reluctant to ride

tricycles, however, with ‘encouragement’ Abrax learnt to use them. I witnessed Abrax seemingly enjoying the experience of cycling in the park on several occasions as in the case involving Ken described in Part One of this chapter. However notwithstanding their ‘best interest’ intentions, witnessing Abrax’s carer ‘convince’ him to do certain things left me with several moral quandaries. I wondered, for instance, if Abrax was being forced into actions against his will, and whether as a researcher, there was an onus on me to report what I thought was malpractice. At the same time I was in little doubt that Abrax and his carers had a great relationship and they had his best interest in mind, as indicated in my reflections below:

Having left the field for the Christmas break I felt heartened by what I thought to be the excellent care that Abrax received [from his carers] (Field notes, 2 January, 2012).

As a contribution to the emerging literature on MCA practice, I have presented data here to challenge the conceptualisation that mental capacity is solely a matter of cognition. Even if Abrax chose among alternatives (as implied by the MCA’s tests of capacity), he still required his carers to fully enact his will. Additionally, his need for his carers’ physicality meant that his desires and theirs were linked in practice – a further challenge to the individualistic model underpinning the MCA. Another way in which Abrax demonstrated his capacity was movement through space instead of ‘passing’ a mental capacity assessment (as implied by the MCA). For instance, when Robert called Abrax from the kitchen, Abrax’s movement of his wheel-chair into the space called ‘kitchen’ illustrated that he understood what Robert said. In a more spatially restricted environment where Abrax could not use his wheel-chair to

mobilise, his interaction with people would be curtailed, and the opportunity to demonstrate his capacity would be denied. Similarly, when given time and space, Abrax was able to eat his croissant. Thus, in Abrax's life, space mattered in relation to his mental capacity. I illustrate this point further in the following section by discussing how Abrax occupied certain spaces in the day centre and how this restricted his interaction with his peers.

Abrax: using space, demonstrating mental capacity

Space is 'a dynamic between social and material relations, which are characterised by power' (Tsolidis, 2008; p273). Whereas currently, in the social sciences literature increasing attention is devoted to space (Holland et al, 2011), there is contrasting silence in debates about the epistemology of mental capacity. In a recent paper aimed at drawing attention to space as a useful analytic category in empirical research, Logan (2012) identified the explanatory power of space to account for human behaviours and choices. This is because space determines distance, which in turn impacted on social relations and/or access to resources. To reinforce his thesis, Logan cited Abbott (1997; p1152) "one cannot understand social life without understanding the arrangements of particular social actors in particular social times and places [...] Social facts are *located*.'" (Logan, 2012; p508; original emphasis). Abbott's cited point here applied to Abrax because, in certain areas with fewer obstructions, he mobilised more freely, thereby reducing the instances he called on other people to enact his will.

Yarlow was recently renovated specifically for wheel-chair users in contrast to the day centre which had more confined space (in the day centre, several service users used wheel-chairs in a constrained space). The tight spatial configuration of the day

centre curtailed Abrax's ability for spontaneous action; therefore, it also reduced the possibility of him demonstrating his capacity. In the day centre I observed that Abrax used specific spaces. Usually he was separated from the main room where most activity took place. After one such observation I made this entry in my field notes:

What is noticeable (as I have observed on two or more occasions) is that while the other users sat together in the 'living area' Abrax was with his carer in the backroom alone besides one female service user who had very high needs and could not communicate nor engage physically with anyone (Field notes, 16 December 2011).

Separated from the living area in the day centre, I rarely observed Abrax interact with his peers other than one young man who always called him 'Eric'. Also, as he was unable to manoeuvre his wheel-chair unencumbered, Abrax typically sat facing one direction, and he often had to make loud noises to be noticed by staff. As I spent more time with Abrax and his carers, I noticed that, in the day centre, I was often left alone with him, as if I were a support worker providing the one-to-one support stipulated in his care plan. I sought to make sense of this realisation and as evidenced in my field notes below, the only explanation that seemed credible to me at the time was that I had earned trust:

In this visit I was left with Abrax for some time. Sitting here now I think that being left with Abrax for long periods by the staff [...] suggests that the staff trust me or that roles are being blurred to the extent that staff consider me one of them. On the other hand it may be that my being

around affords staff time to leave Abrax supervised [by me] to attend to other duties. (Field notes, 21 November 2011).

The data extracts presented in this section suggest that space, which includes the configuration of material objects and human relations, impacted on how Abrax demonstrated his mental capacity. At Yarlow, Abrax inhabited an open-plan kitchen/diner. This open space meant that Abrax could see and be readily seen by staff. Furthermore, he could mobilise with relative ease at Yarlow because the spatial design accommodated his wheel-chair. Within the day centre on the other hand Abrax was restricted because he could not move freely. Besides, the day centre was crowded, noisy, and busy. In the day centre I rarely saw Abrax initiate interaction with his peers; therefore, in that day centre space, he did not display the character to sustain the narrative of 'sociable' constructed by staff at Marigold. Interestingly whereas at Yarlow support workers said Abrax could make decisions or that he was capable, I did not hear carers in the day centre use the same expressions. The conclusion to be drawn here is that the two spaces with their different orientations placed separate demands and, in the process, (dis)empowered him in divergent ways.

Increasingly, the conceptual underpinnings of the MCA, that mental capacity is solely cognitive and individualistic, are coming under intellectual attack, with growing preference for relational models (O'Connor, 2010). Arguably, relational models by necessity require attention to spatial configuration as I have shown above. O'Shea (2012), on the other hand, has proposed an ecological model in which mental capacity is an interaction of the physical and social environments, rather than solely a cognitive function. By drawing attention to the physical environment, O'Shea's postulation is close to the spatial model that I propose here. However, O'Shea's use of

the term ‘ecology’ suggests that mental capacity is a living organism that grows or dies, whereas strictly speaking, in the MCA capacity changes with time and decision, hence the decision and time-specific principles. Capacity is not a living thing but a concept, so ‘space’ which denotes a non-living entity, is a better term for mental capacity than O’Shea’s ‘ecology’, which is arguably more applicable to living organisms. One other concept which any discussion of relational ideas on mental capacity draws attention to, is culture (or ethnicity), which also emanates from social relations, and as such, influences the decisions that people make (McCracken, 1986).

Part Three. Culture and decision-making in Abrax’s adult life

This section discusses the important role of culture in Abrax’s life generally and decision-making in particular. Firstly, I analyse how Abrax lived as a Greek-Cypriot in Yarlow, his awareness of his Greek-Cypriot heritage, and how that impacted on (co)decision-making. Subsequently I discuss the subject-matter from the viewpoint of Abrax’s carers. To accomplish my task in Part Three, I deliberately use ‘culture’ instead of ‘ethnicity’ as an explanatory tool. I recognise the symbiotic relationship between ethnicity and culture; however, I operate the former as mobilisation of the latter: culture operates at the level of lived experience whereas ethnicity is located within institutional or organisational parameters (Malešević, 2011). Abrax required other people to recognise firstly that Greek culture was relevant to his choice-making, and based on this realisation, to present him with options. Consequently, the culture of people within Abrax’s network is also relevant to the discussion because they too, arguably, relied on their cultural frames of reference to interpret his sounds and gestures: ‘culture is the “lens” through which the individual views phenomena; as

such it determines how the phenomena will be apprehended and assimilated.’ (McCracken, 1986; p72). Because Abrax relied on other people’s physicality to fulfil some wishes, the cultural prism through which his carers viewed the world is important to my analyses (O’Dell et al, 2004).

Abrax: living as a Greek-Cypriot

Caughey (2006) advised that one way for researchers to identify people’s culture is to note the artefacts in their living spaces, but in the case of Abrax there were no obvious signs of his cultural heritage. In Abrax’s room at Yarlow, there were many photographs of him and his family on the wall: images captured of him engaged in leisure activities with his family, using physiotherapy equipment to mobilise, and being on holiday. There were also Arsenal Football Club scarves on the wall. If the artefacts surrounding people’s houses signalled their cultural identity then, one would conclude from observing Abrax’s home that, the important issues in his life were family, music, and supporting Arsenal Football Club.

In his everyday life at Yarlow, however, I observed Abrax’s cultural heritage manifested in several ways. At the time of fieldwork, Abrax shared Yarlow with Alexander, who was also of Greek origin. Alexander’s mother Lola visited the house so often that initially I thought that she too was a member of staff, and it was later in fieldwork that I realised her role. Lola interacted with Abrax, and spoke Greek-Cypriot to him daily. Because she visited Yarlow every day, Lola also taught Abrax’s support workers, who were all of African origin, how to cook Greek food for him. Her influence on Abrax and his support workers was noted by Robert when I asked him during an interview how he had been influenced culturally through his work with Abrax:

Godfred: When you see, Abrax use different language for instance and eat different food for instance, does it make you think differently as a Ugandan?

Robert: Yes it does in a way. First of all I've got to learn and understand their diet, food type, how to prepare it, you get what I mean? It's quite different from mine, it's quite different from where I come from, do you know what I mean? Like the preparation and everything. Because since I've been with Eric I've learnt a lot, the cooking, the cooking type, Greek cooking, the parents have helped [...] Lola has helped me a lot in cooking the Greek food, you know what I mean? Now I can cook Greek food. (Taped interview, Robert, 2 January 2012).

As a way of explaining how working with Abrax influenced his cultural identity, Robert in the above interview extract credited Abrax's parents and Lola for teaching him about Greek food preparation. The presence of Lola and Abrax's parents in the quote from Robert illustrates the relational nature of culture for it shows that people learn to live like others who they interact with. In the case of Robert who was originally from Uganda, working with Abrax resulted in his learning to cook Greek-Cypriot food and even speaking certain words in Greek. Apart from showing the relational aspect of culture, Robert's answer above shows that, in his everyday life at Yarlow, Abrax ate Greek food and this can be seen as one way in which Abrax lived his cultural heritage. The presence of Lola and Alexander in his home, together with regular visits from his parents and grandparents, ensured that Abrax remained in contact with important dimensions of Greek-Cypriot culture.

Although I could not directly ask Abrax about his understanding of his Greek-Cypriot cultural heritage, I inferred from some of his interventions in the interviews and from my observations during field work that he understood Greek language. A case in point was 16 December 2011, when I accompanied Abrax and his support worker to the day centre. By now, responding to the advice in the literature that ethnographers should prepare research participants for the end of their fieldwork, I had started the 'getting out' work by reminding Abrax and his support workers about the last date of fieldwork (Iversen, 2009). It was in the context of this conversation with me making 'small talk' that I asked Abrax where he would spend Christmas. On the surface of it, the issues of Christmas and 'getting out' are unrelated but the two became linked in the conversation because I could not tell whether Abrax understood my explanation about 'getting out'. The question of Christmas was therefore my test of his understanding. In my field notes from the encounter, cited below, I wrote about my surprise at Abrax telling me his answer about his location for Christmas in Greek.

Having been engaged with Abrax for a number of weeks now, I have learnt to speak as if he understood me, so I proceeded to ask him whether he would be spending Christmas with his mother. Then he said 'yaya' and I said 'oh you are spending Christmas with yaya' and he said 'yes.' There is absolutely no doubt in my mind that he was telling me that he would be spending Christmas with yaya and that it was not a case of chance. If Abrax understood my question about Christmas, then he must have an understanding of the concept of Christmas; making it likely that he also understood me when I said that I would not be coming to see him again. (Field notes, 16 December 2011).

The data excerpt above shows Abrax responding to my question in English using a Greek word for grandmother, 'yaya'. From my previous interviews with his parents, I had learnt that the Greek word for grandmother is 'yaya' and I also heard Abrax say the word several times during fieldwork. The spontaneity with which Abrax said 'yaya' when I asked about Christmas convinced me that he understood my question. Consequently I did not feel the need to cross-check the information with his parents.

In the above data extract from my field notes in which Abrax and I discussed Christmas, he could be said to have displayed the MCA yardsticks of mental capacity: understanding, retaining, using and weighing-up information to make a decision (MCA Code of Practice, 2007; p41). This was because Abrax showed that he heard what I said through his response to my question in Greek. By demonstrating that he heard my question through his answer, Abrax also evidenced that he processed the question. Finally because Abrax provided an answer fitting within the conversation topic at the time – i.e. his location for Christmas – Abrax may be said to have appreciated the question. The first data extract about Christmas is more akin to the test of capacity proposed in the MCA whereby the assessor proposes the information and makes a judgement on the person's capacity based on their responses.

On another occasion, Abrax demonstrated to me that he could choose between two options presented respectively in English and Greek languages. The data presented below to explain my latter point was recorded from a taped interview with Anthony at which Abrax was present. An interesting methodological point is that, even though Abrax could not communicate in sentences, his carers referred questions I asked about his culture to him. On my part these interviews caused me some ethical discomfort because I talked about Abrax in his presence without addressing questions directly to him. This particular interview with Anthony became centred on the topic of

food and he explained that Abrax was told daily at meal times whether there was a choice of British or Greek-Cypriot food:

Godfred: And, and, if you were getting him to make the choice, would you have to present it to him, would you have to say...

Anthony: Oh yes! Oh yes! Or even if you haven't presented it to him and you've told him isn't it Eric? [Abrax makes sound] If I told you that 'would you like fasolaki or, or mash...what is it called? Mash and bangers for example, wouldn't you chose what you liked?'

Abrax responds 'yeah'.

Anthony: What would you like? [After long pause] Do you see? He knows I said 'fasolaki?'

Godfred: So he's pointing to your right hand side which was [British cuisine and] left hand which was the fasolaki.

Anthony: Now, he has pointed to the right which [he] is identifying with and fasolaki is a Greek dish.

Godfred: What's fasolaki?

Anthony: It is just sort of like a casserole but they put runner beans in it, so it is sort of a speciality and the way they cook it. (Taped interview, Anthony, 28 February 2012).

Our discussion about the choice of food captured in the data extract above is arguably more akin to a relational model of culture and decision-making. From his relationship

with Abrax, Anthony knew that Greek-Cypriot food mattered to Abrax. Consequently, he included falosaki in the options presented to Abrax, and furthermore, Anthony made it possible for Abrax to exercise his choice. An individualistic model would place the onus on Abrax to demonstrate the falosaki was important to him, whereas in the relational model, Anthony presented the choices to Abrax based on his prior understanding of Abrax's culture. The data extracts I have discussed in this section illuminate how culture and mental capacity interacted in Abrax's life. Due to its individualist underpinnings (O'Shea, 2012), a case may be made that the concept of mental capacity cannot account fully for how culture impacts on decision-making because culture is principally a relational (or social) concept: 'culture is universally constitutive of social relations and identities [...] in *contemporary societies* culture plays an unprecedented role in constituting social relations and identities' (Nash, 2001; p78; original emphasis).

A conceptualisation of culture as relational adequately explains some of the decisions made in Abrax's life by his parents. For instance in my interviews with Mr and Mrs Chantos, they told me that they self-identified as both British and Greek-Cypriot: they navigated between these two identities depending on who they were with. With their Greek-Cypriot relatives, their Greekness came to the fore and vice versa with their British friends. The dual cultural positioning of Mr and Mrs Chantos is one aspect of the relational model: those that we associate with determine the cultural frames of reference we draw upon in our lives. In another respect the relational approach of culture and decision-making captures instances in which in choosing between options, we take into account the expectations, privileges, and moral requirements of our culture. As an example of this second aspect of a relational model of culture and decision-making, Mr and Mrs Chantos told me in an interview

that in Greek-Cypriot culture, family members lived together irrespective of age. As such some of their relatives found it unpalatable that Abrax lived away from home. Yet Mr and Mrs Chantos said that even though it was going against their cultural heritage, they chose that Abrax lived at Yarlow because it became increasingly difficult to look after him at home:

Their relatives would not be happy with them allowing Abrax to go [to Yarlow] because their cultural tradition revolved around ‘family’ meaning that Abrax should have remained at home. I remember clearly Abrax’s father saying ‘even some of our family are not happy [with Abrax at Yarlow].’ They said that in the end they felt that it would be the best course of action for him [...] I recall Mrs Chantos saying that despite going against their cultural tradition, Abrax appears happy to be living at Yarlow thereby vindicating their decision. (Field notes, 19 November 2011).

The data extract above depicts my field recording of Mr and Mrs Chantos reflecting on what they thought their relatives made of Abrax living away from them. They recognised that within their Greek-Cypriot culture, their relatives did not welcome news about Abrax living away from home. Even though they took into account the cultural expectations of their relatives, Mr and Mrs Chantos made a different (unexpected) decision because they were struggling to look after Abrax. Secondly, based on their knowledge of him, Mr and Mrs Chantos felt that he would be happier in Yarlow. Their family’s views and his wishes were important aspects of Mr and Mrs Chantos’ decision-making even if familial views did not ultimately influence choice of accommodation for Abrax.

Thus culture is important to the decisions Abrax makes in two respects: he needs people to recognise that his Greek-Cypriot culture matters to him; as such, the options people present to him to exercise choice should take account of his cultural heritage. Secondly, those offering alternatives to Abrax also draw on different frames of reference, one of which is their culture. Based on these postulations, I explain in the next section what Abrax's carers told me about their culture, and how it impacted on their work with him, including the choices they offered him. Strikingly, Abrax's carers told me that they hailed from cultures in which age signified seniority and power to be respected by those younger. Given that they were all older than Abrax, working within a culture in which Abrax made decisions that they had to respect was an inversion of their cultural upbringing. However, as I show later on, in their accounts, the carers argued that their formal education made them understand the superiority of Western notions of choice over their culture in which decisions were made collectively. The life stories of the support workers, therefore, show the multi-faceted nature of culture and ethnicity: how these two concepts are mediated by education, class, place, and employment, and how these impacted on decision-making.

Caring in a different culture

Operating with a hypothesis that contextual factors such as culture, biography, and social relations influence individual decision-making, I now briefly paint a portrait of the support workers.

Portraits of Abrax's support workers

At start of fieldwork, there were three male support workers - Anthony, Robert, and Helder – and they can be said to know Abrax best, having worked with him since he

moved to Yarlow in August 2011. By the time I completed data collection at Yarlow the team had increased to five men: Abbassi began in the same month that I commenced fieldwork while Tom joined the team towards the end. Abbassi worked part-time and Tom was hired principally because Anthony, Robert, and Helder complained to management about their high workload. Until Tom's appointment, Helder, Robert, and Anthony individually clocked over 60 hours weekly on 12-hour shifts. To alleviate their high workload, Tom was hired to work designated hours from 8AM – 3PM daily with the other workers doing the late shift (3PM – 10PM) or night duties (10PM – 8AM).

Noticeably all the support workers were highly educated and their reasons for immigrating to the UK varied: Helder, Abbassi, and Anthony emigrated to complete their Master's degree, Tom to escape civil war in his home country of Democratic Republic of Congo, and Robert to increase his income. In their interviews all five support workers said they were middle class professionals in their countries of origin. Tom and Robert, for instance, told me in different conversations in November and December 2011 that they were respectively university lecturer and accountant:

During the discussion about his biography when he fed Abrax lunch, at my asking, Tom said that he had been a psychology lecturer in Kinshasa and that times were good then. He said that Kinshasa now looked like a village even though it was once one of the great cities of Africa (Field notes, 16 December 2011).

Prior to emigrating Robert said that he worked as an accountant in [a mobile phone company]. He appeared to have a good life. He said that he travelled regularly with work (mostly in first class) and he came to the UK

and Amsterdam regularly [...] It was on one such visit to the Europe (I think that he said Amsterdam) that he saw a recruitment advert for nurses and he completed the form on behalf of his wife (Field notes, 16 November 2011).

Tom and Robert's exposition of their pre-immigration lives as, respectively, university lecturer and accountant, show that in their current role, the support-workers were overqualified. At the same time, being highly educated they could be re-trained to familiarise themselves with the policy context of their role with Abrax, including the need to enhance service users' decision-making.

Based on my (auto)biographical interviews with the support workers, I have produced a table below summarising their personal information. All the support workers hailed from Africa and migrated to England within the past decade. During fieldwork, although I saw Helder several times with Abrax, I was not able to conduct a biographical interview because of the pressures of work. All my attempts to arrange interviews in his home were unsuccessful; as such, in the table I have not included the number of years that he has lived in the UK. However, from our previous conversations Helder told me that he was born in Angola but moved to Portugal at nine years of age.

Name of Support Worker	Country of Origin	Years in the UK	Length of engagement with Abrax	Family status
Robert	Uganda	10	Since August 2011	Married, two children
Anthony	Uganda	8	Since August 2011	Living with white Australian girlfriend
Helder	Angola	Unknown	Since August 2011	Unknown
Tom	Democratic Republic of Congo	3	December 2011	Married, four children
Abbassi	Nigeria	2 years	October 2011	Living with girlfriend

There were two common responses by the support workers to my questions about how (or whether) living in the UK had affected their cultural identity. Irrespective of the length of time in the UK or whether they held British passports, all of them denied being (or feeling) British. A case in point is Tom whose response to my question is shown below:

I learnt that Tom had four children and I asked whether they thought of themselves as British. He said that though the children all had British passports they did not consider themselves as British and implied that the children did not feel British because of the racism that they faced in society. (Field notes, 16 December 2011).

Tom's explanation about why his children (and he) did not feel British because they suffered racism illustrates the common theme in the data about what culture the carers felt they belonged to. Contravening the current understandings of culture as multiple and permeable (Soysal, 2009), the support workers reported being conscious that Abrax and they were of different cultures. In one sense therefore, Abrax reminded them of the black/white dyad. However at the same time, the support workers maintained that Abrax had a dual British/Greek Cypriot cultural heritage which had to be respected in their work. Thus the support workers saw their culture as monolithic and impermeable yet they thought of Abrax as simultaneously living in two cultures (British and Greek-Cypriot).

One person who epitomised the positions held on culture by the support workers discussed here is Anthony. Anthony was of Ugandan origin, lived with his white Australian girlfriend and had a Master's degree. He said in our interviews that he was keen to maintain Abrax's culture, which he thought were British and Greek-Cypriot. Nevertheless, despite maintaining that Abrax had a dual heritage, and even though he himself lived with a white Australian, Anthony did not think that working with Abrax had altered his cultural identity. Anthony said that he separated himself from his Ugandan culture when at work with Abrax. Anthony also explained that universal values underpinned all cultures:

Godfred: How do you think it's [your work has] made you think about your culture?

Anthony: Working with him does not influence anyway how I think about my culture because for me they are two different things, I do not bring it into the mix when I am working. Although as a person, I was brought up in certain ways as well there are certain values that it doesn't matter which culture you are from or who you're working with, if you're brought up properly and you're treating people with respect and you value people, and in my culture that's how it is; it is something that I will still be using to work with him. (Taped interview, Anthony, 28 February 2012).

In the above interview extract, Anthony confirmed that when at work he was mindful of the differences between his Ugandan cultural identity and Abrax's culture. Anthony noted that being Ugandan was separate from Abrax's culture – 'they are two different things' – and he avoided conflating or, in his words, 'mixing' the two when working. Even though he claimed cultures to be separable, Anthony also maintained that cultures were underpinned by similar values and these made it possible for him to work with Abrax.

Drawing on my personal experiences as a Ghanaian, I aimed to explore how support workers being older than Abrax would impact on decision-making. In Ghana, there is a close relationship between age and moral entitlement to 'respect', a cultural practice captured in an ethnographic study of children rights in Ghana by Imoh (2011), a UK-resident Ghanaian academic:

They [children] are not expected to challenge adults and certainly, not expected to question what they are told to do. As a result of the value placed on respect, the need for children to respect and obey their parents and other adults in their community frequently emerged in various focus group discussions [...]’ (p384).

Imoh suggested further that ‘respect’ was a form of inter-generational transfer of duty: the children in her study felt that they had to respect older people in order to receive protection from harm or have their needs met. Thus my cultural upbringing enabled me to identify age as one possible issue that would affect how culture impacted on decision-making in Abrax’s life. Hence, I also sought to understand how the relationship between age, culture, and decision-making played out within a policy context such as the MCA in which cognitive capacity and not age and culture was recognised as the key determinant of mental competence.

Age, culture and decision-making at Yarlow

In my interviews with the support workers, I gathered evidence that like me, they too hailed from cultures in which an older person had the moral right to make decisions for a younger person. However, the categories ‘adult’ or ‘elder’ were necessarily not associated with chronological age but rather depended on the ages and social standing of the addressed or addressee. Thus, whereas in the UK, 18 years of age marks entry into adulthood, in the cultures of the support workers, there was no concomitant landmark age. In their cultures, one acquired the status of adulthood or an ‘elder’ if being addressed by someone younger. In this sense, age was a relational concept in the support workers’ cultures. Robert, for instance, said in our interview that, in his home country of Uganda, relative age accrued ‘respect’ from people younger:

When you're still young, any person who is older than you, even if you're found in the street and you've done a mistake, you've done something wrong on your way from school he's allowed to give you a punishment. Yeah even that person can bring you to your dad or you mum, 'that I've found her doing this one, I've given him this punishment' and your parents will give punishment again as well [...] you respect anybody older than you, respect, even the moment I see you I stop doing what I'm doing? (Taped interview, Robert, 2 January 2012).

In the passage above, Robert's explanation drew on absolute and relative notions of age. In the first part, Robert talked about 'young' in relation to school age so that someone at school was by corollary a child. Anyone out of school was therefore older and could mete out physical punishment if the child transgressed a behaviour code. In absolute terms, older people therefore had moral right of parenthood and, as such, could discipline any child. Robert suggested, further, that parents would not contest or challenge physical chastisement of their child by another older person. Of further interest is Robert's assertion that even the child's parents were more likely to 'give punishment again as well'. It may be that parents mete out further punishment because ill-discipline by their child outside the home suggested that their parents were unable to set boundaries. Moving on from childhood, in the last sentence of the passage, Robert made a pronouncement on relative age – i.e. 'you respect anybody older than you.' By this last statement Robert confirmed the power that accrued to an older person to make decisions for those considered younger.

At the same time that they confirmed the power of ‘elders’ to receive respect, some of the support workers indicated that exposure to Western ideals had led them to question this moral code. Firstly, even before they moved to the UK, through their high(er) levels of education they had become exposed to Western lifestyles in large cities, and in these spaces, there was relative egalitarianism. According to Anthony (also from Uganda), his self-reflection on the (un)desirability of aspects of his Ugandan culture started before he came to the UK through his education and living in the capital city of Kampala. He explained in our interview that Kampala is a metropolis which is ‘Westernised’ with an educated population. When he lived there, Anthony saw at first hand women in powerful positions, leading him to question his cultural upbringing which stressed men’s powerful roles in society:

I mean there is a difference in the West and I think it is good the way they do it in the West it shows there is equality. In cities [in Uganda] there is a change but in villages, there are still people who [...] still want women to be below them and I don’t think it is a good thing personally. (Taped interview, Anthony, 28 February 2012).

As a continuation of his reflection on the differences between Ugandan and British culture, Anthony said that through training and further self-reflection, he now believed in the inalienable right to choose as epitomised in liberal democracy:

I’ve been trained as well to promote independence for example, to allow people to have choices and this is all about the quality of life that someone - everybody, you, Eric, me – we are not different, we are all people...and

it would be a shame if for you, Godfred, you were not allowed to make your choices...supposing you liked doing something and then someone said you can't do it and there is even no reason for them, for them to tell you not to do it or stop you from doing it; that would be taking away your right. (Taped interview, Anthony, 28 February 2012).

The preceding quote from Anthony suggests that he believed there were several reasons why he needed to offer or enhance Abrax's choice. To Anthony, choice was tantamount to wellbeing – 'quality of life' – and, as such, a denial of choice resulted in 'shame', a word which also means 'degradation' in everyday usage. Furthermore, Anthony conceptualised choice-making as one of equality – 'we are all people' – and of not engendering choice as deprivation of human rights; 'that would be taking away your rights.' 'Rights'; 'quality of life' and 'equality', by which Anthony justified his convictions about the moral imperative of choice are all embedded in current learning disability policy (DOH, 2009). Anthony's statement suggests that even if he hailed from a different culture, through 'training' he has grasped the values espoused by current policy on learning disability. This latter point also potentially explains how professionals completed the Learning Log in the first person 'I'. The two quotes above from Anthony, also exemplify how culture, education, and place interacted to impact decision-making on Abrax's care. On the basis of the support workers' cultural heritage alone, age denoted power to make decisions for those younger. However, Abrax's age combined with the policy environment of their employment, which stressed autonomy, inverted the support workers' cultural understanding of the relationship between age and power. Nevertheless their education and their original middle class backgrounds prior to emigrating provided bridges to cross cultures.

Firstly, because of their education some of the support workers – for example Helder, Robert, Abbassi, Anthony - viewed the doctrine of choice (and by implication individualism) as a plausible alternative (or even more superior) to their cultural heritage, which sometimes emphasised collective decision-making. Secondly, even if they did not hold the view that choice mattered to people, through their training, they could consider the need to promote choice as a necessary part of their duties as support workers. However, while the support workers unanimously espoused the view that Abrax had mental capacity to choose, or that they believed in the right of every service user to choose, they did not always offer Abrax alternatives. In the next section I analyse data to show how the support workers' cultural understanding of food led them to overrule Abrax's choices. What was conspicuous in my observation was Abrax's response: in each case he responded to food being pushed into his mouth by being violently sick. While I interpreted his actions as resistance on his part, the support workers believed him to be ill.

Food and the limits of cultural intermingling

The two incidents that I describe here both happened at breakfast. The first instance was on 18 October 2011, about a week into fieldwork. While Abrax was having his breakfast of porridge and croissant, he gestured that he was full but Anthony continued to feed him, whereupon Abrax violently regurgitated his food. Even at the time I interpreted Abrax's actions as resistance, as I recorded in my field notes:

Anthony encouraged Abrax to finish the last portion of the porridge. I cannot recall how this conversation came about but it may be that he read an action from Abrax that he did not want to eat anymore. But immediately after this, after he put another spoonful into Abrax's mouth

Abrax began regurgitating the food and Robert put the bowl under his chin. Robert then talking to [female support worker] said that he thought that Abrax's body suit sometimes caused him to regurgitate food. But at the time I wondered whether the regurgitation was a deliberate act of resistance by Abrax that he did not want to eat anymore. (Field notes, 18 October 2011).

The second occasion that Abrax became violently sick after being made to eat against his will involved Helder and closely resembled the first. The data extract below illustrates the complex interactions that occurred between Abrax and Helder, and how the latter's culture influenced his decision-making about Abrax's feeding. The backdrop to the incident about Abrax becoming sick after eating was that Helder had maintained beforehand that Abrax could make decisions for himself:

He [Helder] said that Abrax was outgoing and that previously they planned his community activities a week in advance; however, these days Abrax chooses his plan daily because that is what he likes doing. Helder said 'well you will see, as you get to know him you will understand'. (Field notes, 14 October 2011).

Implicit in Helder's statement above, is that Abrax told his carers daily what he would like to do. Despite espousing the view that Abrax could make choices, Helder overruled him on the issue of eating. During fieldwork on 16 November 2011, I arrived to see Abrax eating breakfast, which I could tell immediately, was 'African.' Abrax stopped eating but Helder encouraged him to eat more, and when he would not Helder pushed more food into his mouth which caused Abrax to vomit violently. As is

noticeable from the data extract below, even at the time of compiling the field notes, I wrote myself into the data, in that I clearly realised that it was my life experiences growing up in Africa which enabled me to, firstly, identify the breakfast as 'African' and secondly, provided means of interpreting Helder's actions.

I noticed in sitting next to Abrax (who was again facing the window) that he was eating [a sandwich] breakfast of hot cross bun with processed ham in it. This breakfast caught my attention as particularly 'African'. I noticed also that Abrax did not eat anymore for several minutes and he became sick not long after Helder had pushed one of the portions [of food] in his mouth. I remember Abrax's sickness was sudden and it occurred to me that on the first time I noticed him sick this was after food had been similarly pushed into his mouth. (Field notes, 17 November 2011).

Notwithstanding his expressed views that Abrax was capable of making decisions, Helder did not feel the need to ask him about whether he was full before pushing another portion of food into his mouth. Abrax's subsequent regurgitation may be interpreted as his act of resistance or that he had a stomach bug (as his carers subsequently claimed). However, an interpretation based on an insider perspective – as a Ghanaian (and African) - arguably yielded more fruitful analysis about the moral significance of food to Helder, and how this led to the interactional outcome shown in the data extract above.

From my life experiences food (and especially meat) has centrality to some people who would consider themselves as of African origin, and it may be that this is

what led me to immediately realise the ‘African’ nature of the breakfast on entering Abrax’s home. In most African countries where food is less plentiful, it is not to be ‘wasted’ and one is not allowed to have an unfinished meal if only because most people have diminished access to food. Eating and completing a meal is, therefore, not only a matter of personal nourishment or personal expediency; it also has moral significance because leaving a plate uncompleted showed profligacy. Moreover high food intake epitomised in weight-gain suggested prosperity (Rehanzo et al, 2012). Eating, and therefore weight-gain, had powerful moral significance beyond the need to survive. For instance in 2011, a Ghanaian woman was prosecuted at the Old Bailey (High Court) for force-feeding her baby²². Following an investigation into what was perceived to be inadequate professional response, one explanation for professional inaction to the risk accruing to the baby from force-feeding was limited understanding of the cultural value of food to his mother: ‘Practitioners were insufficiently sensitive to obtaining an understanding of the significance of cultural and/or individual values with regard to weight, body image and feeding practices.’ (London Borough of Waltham Forest Children Safeguarding Board, 2011; p3).

My analysis here is that Helder, being African, would have seen it as his moral duty to ensure that Abrax finished his plate of food. Stemming from this Helder, despite espousing a discourse of choice which would necessitate his ascertaining or respecting Abrax’s mental capacity to refuse further feeding, Helder chose to push the food into his mouth without asking. Helder would not offer a choice to Abrax as to whether he ate more or not as Abrax had to have the food to fit into Helder’s cultural and moral frameworks around food. Helder’s force-feeding of Abrax and the latter’s

²² < <http://www.bbc.co.uk/news/uk-england-london-15689864> > (accessed on 19 June 2013).

response through vomiting is also reflected in some of the debates in mental capacity with England. Tan et al (2006) have argued that people suffering anorexia should be forced fed because the condition displaces a person's mental capacity to understand the symbolic value of food, eating and nourishment.

Rounding of the discussion, in Part Two, I have taken analytic excursion around culture, showing how peoples' cultural lived experience was a key contextual factor in their decision-making for Abrax's life. Culture was present in Yarlow and in Abrax's life. Unlike in Kotoka, professionals in Yarlow were happy to discuss their culture, and how it affected the decisions they made about Abrax's care. At the same time, the discussion in this chapter has shown that while people in Abrax's life had a strong sense of their culture, they also acknowledge that it was shaped by other variables such as place, age, employment, and their own preferences. In the case of Mr and Mrs Chantos, culture was sometimes mediated by what they felt was in Abrax's best interest instead of their families'. While the modulating effect of other variables on culture and decision-making can be acknowledged, it nevertheless challenges current postulations of mental capacity as solely a cognitive activity of the brain. If anything, mental capacity is more akin to other social categories which emanate from social relations and power.

Conclusion

In this last data chapter I have narrated Abrax's life story using the concept of critical moments to identify key periods in his childhood and how these map onto the three substantive concerns of my research, namely: learning disability, ethnic identity, and mental capacity. Abrax's life story provides insights into how social categories operate. Abrax acquired the category of learning disability through the education

system, yet he might also have been classified as physically disabled because he required other people's physicality in his everyday life. Taking Abrax's life story as a case in point, an argument can be advanced that social categories are not necessarily acquired because of people's inherent characteristics but through chance. For instance, although from birth Abrax did exhibit control over his physique, it was his mind that became the focus of disability categorisations. In another sense, therefore, Abrax being classified as learning disabled exemplifies the binary nature of statutory classifications. A parallel conclusion to draw from Abrax's life story is that social categories become reified. From the accounts of Mr. and Mrs. Chantos, medical professionals were puzzled by Abrax's higher than expected level of understanding alongside his inability to vocalise his thoughts. Furthermore, Abrax in his social life, gained more skills with age, and was perceived to understand complex concepts in comparison to his peers at school or in the day center. Thus the label of learning disability does not capture the sophisticated texture of Abrax's abilities nor is the category adequately variable to express Abrax's intellectual development since childhood.

In terms of current understandings of mental capacity, Abrax's adult life provides grounds on which to challenge them. At the time of my fieldwork, Abrax had not undergone a formal capacity assessment. Within his close social network, however, it was believed that he could make decisions for himself. Abrax's carers and family felt that they knew his mental capacity on the basis of their knowledge of his day-to-day life. With each daily interaction, the range of his carers' understanding of his mental abilities increased and their views about his capacity revised. Based on these ongoing revisions, it may be argued that knowledge about a person's capacity accruing from day-to-day interactions will display multiplicity, change, and

flexibility, rather than fixed statutory assessments. Moreover, in Abrax's social network when people decided on his best interest, it was within the context of his rich social relations rather than his preferences alone. People made best interest decisions for Abrax based on how his wishes would impact on the care arrangements between his five male carers, his flat mates at Yarlow, and lastly, his parents' wishes.

Taking a broader perspective, while my thesis is not a comparative study, there are some marked differences between the first two data chapters on Kotoka and the case study of Abrax. In Kotoka professionals were concerned with risk whereas in Yarlow at no point did I hear professionals refer to Safeguarding Adults policy framework. Furthermore, unlike at Kotoka, in Yarlow ethnic identity (and/or culture) was visible in that I heard different languages spoken, people talked uninhibited about their culture, and professionals acknowledged their difference(s) from Abrax. From my perspective as a researcher, ethical concerns were also different. Whereas in Yarlow I was pre-occupied with the impact of Abrax's mental capacity on fieldwork (inter)relations, in Kotoka I was concerned about how my presence was impacting on the work of the team. These issues outlined in this last paragraph led me to make decisions with methodological and epistemological consequences, on which I now reflect in the next chapter.

CHAPTER EIGHT. REFLECTING ON THE METHODOLOGICAL IMPACT OF IDENTITIES

In this chapter I introduce new data as part of my reflections on the ethics of my research, and how my identities as a black man (British of Ghanaian origin), PhD student, and qualified social worker shaped fieldwork. By general acknowledgement, ethnographic researchers should attend to ethics because they interact with people over a period of time and are, therefore, more likely to impact on their lives. Thus, Murphy and Dingwall (2001) advice that ethnographic researchers should: seek to avoid harm to participants; seek to bring about some good and not use participants simply for research purposes; respect the autonomy of participants; and finally, treat all participants equally. However, in my research, ethical concerns are amplified because of the involvement of Abrax, who was classified as learning disabled. Research involving learning disability service users is considered to present novel ethical issues in two areas. Firstly, how researchers elicit consent and secondly, how they prevent coercion. In Part One, I explain how I addressed these two ethical issues in my research. Subsequently, given that I attentively relied on my identities to accomplish my research aims, in Part Two of this chapter, I reflect on the impact of my respective position(ing) as a black man, PhD researcher, and social worker. It is necessary to engage in this self-reflection because I drew on my biography to pose questions on culture and to interpret some fieldwork observations.

Part One. The (im)possibility of knowing: mental (in)capacity and fieldwork ethics in Yarlow

In Part One, I explain how I assessed Abrax's mental capacity and reflect on the knowledge gained from that experience. Finally I explain how I ethically managed fieldwork relationships with Abrax and his carers.

Assessing Abrax's mental capacity

On first meeting Abrax it was apparent that he displayed some understanding of everyday communication. Below, I have reproduced the field notes I recorded following my first meeting with him to assess his mental capacity. In the field notes I have observed that Abrax could tell that I was the person whose photograph was on the Participant Information Sheet I showed him. To contextualise the forthcoming discussion, I now briefly recount what led to the events I have described below. In my first meeting with Abrax, among other aims, I wanted to gain some perspective on how much of my research he understood. While I explained my research to Abrax, one of his carers, Robert, took images of our encounter on a digital camera. Robert then gave me the camera so that I could browse through the digital images to learn more about Abrax's life. Scanning the photos with Abrax, I thought I would use the opportunity to gauge what he remembered about himself, his understanding of verbal communication, and the consistency of his choices:

As I explained the Information Sheet to him [Abrax] Robert took photos of the process. He left the digital camera on the table and said that I could look through some of the activities that they arranged for the service user.

So I was flicking through the photos with the service user looking and I would ask him ‘who is that?’ and he would point to himself if he was in the image on the camera or he would point to me [if it was an image of me]. He was accurate every time. (Field notes, 11 October 2011).

As well as evidencing that Abrax understood some verbal communication, the field notes above also show that my framework for assessing Abrax’s mental capacity was ethically robust. This is because I exceeded statutory advice about assessing capacity to involve people in research. Strictly speaking, the MCA solely requires the researcher to assess someone’s capacity to participate ‘on the balance of probabilities’ of their understanding of the research and its accompanying risks (Dobson, 2008). However, in my case, had I focused primarily on my research during my first encounter with Abrax, I would have missed out on the other aspects of his life in which he displayed understanding of complex concepts. For instance, on my first visit, I observed him and his carers in their ‘normal’ routines and Abrax’s understanding of these, the way his carers elicited responses from him, and his personality. I observed Abrax and his carers communicate about their everyday activities, I also paid attention to their interactions, and Abrax’s responses to verbal communication. After spending a few hours with him on my first visit it became clear to me that Abrax understood more about his everyday life and general living than a formal capacity test, focused on the narrow issue of consenting to research, could ascertain.

Even so, after the three visits to Abrax I concluded that, for the purposes of research, Abrax lacked mental capacity to consent to his participation. I could not evidence that he understood my research aims despite my conviction that, beyond the

aims of my research, Abrax understood a lot about 'everyday' living. On every subsequent visit he showed signs that he recognised me, and he was also friendly towards me by holding my hand. However, I could not conclude that he understood the totality of the research nor could I, as a researcher, find ways of drawing out that evidence from him. Stemming from these issues, I assessed that Abrax lacked the mental capacity to consent to his participation, a decision which triggered the MCA safeguards around the need to consult other people. According to the MCA, when it is clear that a prospective participant does not have capacity to consent, then the researcher is obliged to nominate a consultee. A professional, friend, or family member, the consultee's role is to 'assent' to the involvement of the person adjudged to lack capacity (DOH, 2008). In addition to the consultee assenting, the researcher is required to consult them regularly and brief them about how the research participant lacking mental capacity is faring in fieldwork. It is, therefore, due to my uncertainty about Abrax's capacity to consent that I appointed his parents Mr and Mrs Chantos as consultees. As I showed when I discussed my research methods in Chapter Four, Abrax's parents served as consultees and participants in my research,

Additionally, I chose to nominate Mr and Mrs Chantos as consultees because, from my conversation with Annikka (social worker in Kotoka, discussed in Chapters Four, Five, and Six), I learnt that they played an active role in Abrax's life. Also, when I first visited Yarlow, my conversations with his care workers suggested that Abrax was very close to his parents. I reasoned that as well as acting as consultees, Mr and Mrs Chantos could provide valuable data on Abrax's 'critical moments' (Thomson et al, 2002). Choosing Mr and Mrs Chantos as consultees also enabled me to discuss Abrax with those who knew him best; thereby gaining a better understanding of his likes and dislikes. My decision on consultees was justified, given

the rich accounts Mr and Mrs Chantos gave of how Abrax became categorised as learning disabled, as I have shown through the case study in Chapter Seven. However, notwithstanding my assessment that Abrax could not consent to his participation in my research, in my everyday engagement with him, I operated within the ethical framework that I had to directly seek his views.

My ethical decision to seek Abrax's views directly, despite my assessment that he was unable to consent had upsides and drawbacks. On a positive note, Abrax surprised me continuously with his level of understanding. For instance, he understood the concept of medicine, and could tell me that he did not take medicines daily. I found this out on one visit. Knowing that learning disabled service users were routinely medicated, I wanted to know this about Abrax. So I asked him during breakfast, out of context of any prior discussion about medicine 'do you take medicine every day?' and he responded by shaking his head. The fact that Abrax did not take medication daily – only when ill – and yet he was able to tell me that he did not take medicines shows how much information he retained and understood. As such, I assumed that Abrax understood communication, yet sometimes I was proved wrong. On one occasion I was with Abrax in his room looking at the photos of his siblings (one of the carers had previously shown me the pictures). When I placed my finger on the photo of his sister and asked Abrax 'is this your sister?' he said 'no.' The example I have just cited shows how Abrax sometimes seemed unfamiliar with some of his immediate surroundings at the same time as he displayed more cognitive awareness than I had imagined on other occasions. Thus one challenge of fieldwork with Abrax was grasping the uncertainty about his mental capacity and its implied ethical challenges.

Uncertainty: challenging epistemologies and methodologies of mental capacity research

Because Abrax regularly surprised me with his level of understanding, my recurring emotion throughout fieldwork was uncertainty, an issue which I now deliberate further upon in response to the call for reflexivity in social science research (D'Cruz et al, 2007; Hammersley and Atkinson, 2007). Paralleling the reflexive turn in sociology, increasing attention is being devoted to the methodological impact of emotions as researchers challenge the tendency to place emotion and reason as binary opposites (Blackman, 2007; Holland, 2007; McLaughlin, 2003). In my fieldwork with Abrax, my feeling of uncertainty about his mental capacity caused me to be more observant and to seek multiple sources on emerging significant data. One illustration of how I used the feeling of uncertainty about Abrax's mental capacity methodologically involves different stories that I was told about Abrax's capacity to direct people to his grandmother's house.

In the course of fieldwork, accounts emerged from various people that Abrax could direct any new care workers to his grandmother's house, if asked the right questions. These accounts were significant data because they suggested that Abrax had a good memory, and that he had an awareness of the spatial configuration of the area where he grew up. Then when I first visited Abrax's parents, unprompted, they both repeated the aforementioned stories, as shown below in my field note extracts:

Abrax could direct someone from Morrisons to maternal grandmother's house: Abrax's parents told me this within the context of the discussion about his memory and understanding. I recall Mr Chantos saying that the

distance between Abrax's maternal grandmother's home and Morrisons is not that far and he intimated that this should not detract from Abrax's capacity for memory...I recall telling Abrax's parents that I thought that sometimes his answers are inconsistent and they said that it may be that sometimes he jokes – Abrax's mother recounted a story here about Abrax apparently wilfully providing the wrong directions to someone previously.

(Field notes, 17 November 2011).

There are a few noteworthy points from the above data extract. I recorded that Mr Chantos downplayed Abrax's capacity to provide directions by highlighting that the distance between the supermarket, Morrisons, and his maternal grandmother's home was not that far. In the course of the conversation about memory, I also attempted to provide a contrasting view. I mentioned that Abrax sometimes provided inconsistent answers so one could not be certain about his memory, or understanding, or his ability to direct people to his grandmother's home. As recorded in the field notes extract above, Mrs Chantos acknowledged the inconsistency in Abrax's answers and explained it as a 'joke'. Later on in my fieldwork, the issue of Abrax's ability to provide directions to his grandmother's home came up again when I accompanied him and his care worker, Abbassi, on the bus. Abbassi was dismissive of the story, and he suggested that such accounts of Abrax's apparent mental capacity only served to put pressure on him:

On the bus I asked Abbassi if he thought that Abrax is aware of the route. This led Abbassi to tell me that when he first started he and Abrax had to go somewhere and when he asked another member of staff for directions

they said that Abrax would show him. However on the way Abrax could not show him the directions and appeared to answer 'yes' to Abbassi's questions about getting to their destination. This led Abbassi to say that he felt that too much was expected of Abrax sometimes (Field notes, 04 November 2011).

My account of the conversation with Abbassi about Abrax's memory (reproduced above) was contrasting data to what I had been told by another care worker and Abrax's parents. Substantively I felt that different stories about Abrax's abilities required further exploration so this caused me to observe Abrax even more closely. One day, I was sitting next to Abrax on the bus, when we drove past the local library. Abrax became animated, making sounds to the effect of 'ya ya' and pointing to the street. By now I knew that 'ya ya' meant grandmother in Greek, and from the previous conversations, I could tell that Abrax was saying that his grandmother lived in that direction. The account that I have given up to this point is one of my motivation to look for contrasting or affirming data about Abrax's mental capacity because of my feeling of uncertainty. Although I had assessed that Abrax could not consent to his participation in the research, in fieldwork I did not consider my initial assessment as 'closure'.

The emotion of uncertainty I felt in fieldwork with Abrax potentially has broader theoretical, ethical, and methodological ramifications in research on mental capacity. The MCA, arguably, reflects positivist theorisation of mental capacity as 'objective.' As, Charland (1998, 2001) has argued, positivist understandings of mental capacity side-line emotion by taking the view that it distorts rational thought. In this regard Charland proposes that emotion is required for decision-making:

To say that an individual appreciates the nature of a treatment decision in the sense that they can properly evaluate its personal meaning and significance, requires the capacity for emotion as well as the traditional "cognitive" capacities [...] Emotions are the source of many of the most basic human preferences, which, in turn, help to shape and define many of individuals' most important goals and values. (Charland, 1998; unpaginated).

Charland aims to challenge the dominant epistemology of mental capacity by arguing against theoretical separation of emotion and reason, and the implicit association of rationality with capacity. Thus according to Charland, in place of the current position that people in a heightened state of emotion are not capable of making 'rational' decisions, emotion and reason should be considered symbiotic. However Charland's takes his argument from the viewpoint of people undergoing assessments. I, on the other hand, am arguing for considering emotions as part of the epistemology of mental capacity from the standpoint of the assessor.

My fieldwork experiences provide an alternative view that as well as cognition, emotions are necessary for judging mental capacity. If, as the MCA suggests, mental capacity should be assessed 'on the balance of probabilities', then, assessors cannot claim certainty in their judgements about capacity. Judging from my experiences in fieldwork it would seem that assessors themselves can rarely be certain that their assessments are correct. In this regard emotion may be positive, if only by causing assessors to re-check their judgments. Two further points on ethics and methodology flow from my argument. If assessors cannot be certain about their

assessments, this entails the ethical need for them to be transparent about their doubts. Methodologically, if capacity assessment is a matter of probability as advised by the MCA Code of Practice (TSO, 2007), then arguably the qualitative paradigm is more suitable for mental capacity research. This is because qualitative methods pay more attention to contextual factors (Seale, 1999), and in the case of the MCA, these would include the values and emotions of the assessor and those assessed. Additionally, quantitative methodology would in likelihood reify mental capacity by measuring it as a stock in time when decision-making capacity is understood to fluctuate in the MCA.

Up to now, I have discussed how I assessed Abrax's mental capacity, my realisation that his capacity was to some extent indeterminable, and how this caused uncertainty in my fieldwork. While the discussion to date has focused on theoretical and methodological issues, in the next section, I discuss how uncertainty impacted on human relations in fieldwork.

Crossing boundaries?

Another aspect of Abrax's mental (in)capacity that impacted on fieldwork relations was whether or how he understood my relationship with him. I had to consider if he saw me as a 'friend' or care worker. Furthermore, I was aware that I had to carefully manage any expectations about my role in his life at the time, an issue complicated by the fact that I could not ascertain his views. The matter of blurred professional/personal friendship has long been recognised in ethnographic research with learning disabled service users: 'When ethnographic methods are employed, especially within people's own homes, concerns about intrusiveness may give way over time to worries about setting up expectations of continuing friendship which might not then be realised.' (Stalker, 1998; p10). Stalker's caution about the possibility of role conflation was relevant from the outset of my engagement with

Abrax, as we discussed another day that I could visit. A date was suggested by Abrax's carer, which I said was unsuitable for me because I needed to be at the Open University for supervision. Immediately after my response, Abrax started making a noise and jabbing his finger on the table which all present interpreted as a sign of agitation. The data extract below from my field notes on the first encounter picks up the story:

We appeared to have settled on Friday at one point but then I remembered that I needed to be in Milton Keynes for supervision so I said that it may not be possible. At this point the service user began pointing his fingers on the table whilst at the same time making noises which suggested his distress. Both Robert and I knew from the sounds and the actions that the service user was indicating that he was unhappy with me not coming on Friday. I think that I did say that I understood that he was unhappy and that I would be coming on Friday after all. So we agreed that I would come on Friday at 8AM to see him prepare to go out to the center. I can surmise that the service user agreed with this arrangement because unlike previously there was no protesting. (Field notes, 11 October 2011).

At the same time as demonstrating that Abrax understood verbal communication, the exchanges that I captured in my field notes cited above caused me to wonder about the fusing of professional/friendship boundaries. Although Abrax's family visited him frequently and he had a close relationship with his carers, throughout fieldwork I was uncertain whether he understood that my visits were not permanent, or that I was a researcher not one of his care workers, or a friend. Relatedly, once fieldwork was underway, I felt accepted by Abrax and his carers. It seemed that most of my requests

would be acceded to. Sometimes I was even invited to witness Abrax's personal care. Thus, apart from the possibility of conflation of my role as researcher with friendship, it seemed that Abrax's privacy would sometimes be compromised if I accepted every invitation to observe him.

One of my self-imposed ethical rules was, therefore, to decline any offer to observe Abrax's personal care in the mornings even when Abrax gave the permission that I could do so. Throughout fieldwork, Abrax's carers maintained that he 'chose' his outfits in the mornings; he decided when he woke up, and the time that he would have his personal care. As a matter of fieldwork, I was keen to know how these decisions were made by Abrax but at the same time, I was convinced that answering these questions would constitute my crossing an ethical boundary and transgressing Abrax's privacy. To maintain or perhaps more appropriately contain my identity as a researcher, I always arranged a day for my next visit with Abrax and his carers; thus Abrax and his carers controlled the schedule for my visits instead of the other way round. Also, responding to Angrosino and Perez's (2000) call for participant observation to be a context for interaction, I spoke to Abrax and the carers, but I declined any offer to partake in any activities that could be misconstrued as care workers' tasks.

But as I now explain, the boundaries between care worker/researcher were sometimes deliberately tested by Abrax's carers. A case in point was that on one visit in the morning Anthony asked me to feed Abrax his breakfast. Although I declined, Anthony was persistent and at one point enlisted Abrax's support, 'Abrax should Godfred feed you breakfast?', to which Abrax said 'yes.' This exchange around breakfast put me in an ethical quandary because I felt that I would be crossing the boundary between researcher/care worker thus potentially confusing Abrax about my

role, but also being manipulated by Anthony. On this occasion, quick thinking on my part resolved the matter because I told Anthony that the Open University insurance for my research probably did not cover my feeding Abrax. In the field, I had to operate by self-imposed ethical rules in addition to the ethical codes and undertakings given to SCREC.

In Part One of this chapter I have shown how, as a focus of my research, Abrax's identity as a service user, as an individual labelled as learning disabled, and assessed by me as not able to consent to his participation in research, affected methodology and fieldwork relations. Motivated by the principle of inclusivity, I aimed to involve persons likely to lack capacity to consent to their involvement in my research. As such, ethical sensitivities were amplified from the outset of my thesis. Yet the actual practice of fieldwork led to moral complications unanticipated in my application to SCREC for ethical approval. The statutory ethical approval process requires the research to judge mental capacity of prospective participants, and in this way, there is an underlying assumption that capacity can be captured. In my research I found that I could not determine Abrax's capacity, so I decided to appoint consultees. My uncertainty about Abrax's capacity also caused me to be more observant and seek out data to refute (or confirm) my uncertainties. At the level of personal relations, I could not be certain that Abrax understood my temporary role in his life, making me anxious about whether I could live up to his expectations. Part One has, therefore, focused on Abrax. In Part Two, I explore how my identities as a black man of British nationality, a PhD researcher, and a trained social worker impacted on fieldwork in Kotoka and Yarlow.

Part Two. Using my identities as a research tool

I start this section by discussing how my social work professional identity shaped fieldwork. In qualitative research it is accepted that researchers' views of the world and their life histories mould knowledge production. Calling the latter acknowledgement 'epistemic subjectivity' Breuer et al (2002) argue for transparency and accountability in how identities impact on research. It may also be said of Breuer et al's exposition of subjectivity that both the researcher and their participant(s) bring to the research encounter their life histories, personalities, and emotions, which together shape the social situation of the research, and by corollary, data generation, analyses and representation. Correspondingly, subjectivity entails elements of ethics because parties bring to research relations their senses of right and wrong, and how people should be treated.

Social worker

Being familiar with Kotoka from my previous employment as a social worker in the Disabled Children's Team, I felt that my employment experiences would be methodologically advantageous. I thought that I would be familiar with some of the work processes, the documentation, and the professional discourse of statutory social work. Once fieldwork started however, I realised that my experiences as a social worker counted for very little in terms of data gathering as I recorded after my first day in Kotoka:

Contact with the field has also surprised me about how little my social work experience counts here. For one thing this is an area of social work that I knew little about in detail so in a sense I am learning a new aspect of social work which I find fascinating (Reflective Diary, 10 June 2011).

In Kotoka I was unfamiliar with the work processes and discourse as my fieldwork was sited in adult services. When I practised as a social worker, 'risk' was mitigated through the process of child protection and the legislative framework was the 1989 Children Act, whereas in adult services, safeguarding is the preferred term. The procedure for allocating cases in the integrated learning disability team was different, and as a child care social worker, I was part of a standalone social work team, whereas Kotoka was an integrated team. While during my period of practice multi-disciplinarity was regularly talked about as a policy aim, it was in Kotoka that I first experienced the practice implications thereof. Moreover, the time spent doing a PhD had lessened my familiarity with office environments and everything in Kotoka initially seemed fast-paced. As I recorded in my Reflective Diary on 06 June 2011: 'there is so much more that goes on in an office than I ever imagined would be the case.'

My solution to the unfamiliarity of the research setting was to work harder and concentrate more so as not to miss anything during observations. I wrote copious amounts of notes, asked questions, and soaked up any information I came across. Later, once the professionals and I had developed a personal relationship, they said that my interest in their work was endearing. However fieldwork was emotionally and physically draining. I was also consumed by the possible (im)morality of my presence in Kotoka and I was also determined to stick to the agreement with SCREC that my

research would be non-interventionist. Initially because of the ‘non-interference’ commitment to SCREC, I sat around the office not talking to people, and predominantly observing, giving rise to an intense feeling of voyeurism. At other times I was pre-occupied with the ethical principle that I was not to impose my will on other people. Sometimes I heard professionals discussing needs of service users who were part of my caseload when I practised as a children’s social worker but I did not feel that I could ‘reveal’ my knowledge, lest I be seen as ‘interfering’ in case work. Similarly, when I saw faces that I recognised from my period as a children’s social worker, I did not want to renew old acquaintances for fear of blurring roles. Altogether, in the initial stages of fieldwork in Kotoka, I expended a great deal of energy working out what constituted ‘non-interference.’ With time, instances occurred to suggest that my presence was eliciting performances from professionals or that people were engaging in activities which they had designed for me to record. Here it may be said that my positioning as a PhD researcher was impacting on data generated.

A researcher capturing staged performances

My identity as a PhD researcher played out in different and interesting ways during fieldwork in Kotoka. Sometimes I was positioned as the resident expert on the issue of mental capacity, and attempts were made to draw me into professional discussions. An example was a Safeguarding Meeting I attended which was called because of reports of domestic violence against a service user. The social worker introduced me at the meeting and the chairperson asked about the topic of my PhD. As the meeting evolved and a solution to the case seemed intractable, the Chair turned to me and asked how domestic violence affected people’s mental capacity. I have reproduced the relevant field notes below:

Chair turned to me and asked how [domestic violence] affects someone's capacity to make decisions: Recalling the exchange with the chair I feel that she was asking two questions: one whether (and how) domestic violence affects someone's capacity to make decisions and/or how you resolve a domestic violence issue where the service user has capacity to decide to stay in the relationship with the alleged culprit. I recall giving an answer to the effect of whether the person understands the risk. At the time I felt that my answer sounded silly but I was also keen not get too involved; to become the resident expert. (Field notes, 14 June 2011).

The above field note can be interpreted along the lines that I was deemed by the chair to have knowledge to resolve the dilemmas of the meeting; therefore, I was placed in a position of power. At the same time throughout the meeting, I questioned myself as to whether my presence had led to the prolonged discussion about mental capacity and culture. As I later captured in my Reflective Diary, I was unsure as to whether, were I not at the meeting, the discussion would not have taken a different trajectory:

A question that I may not be able to answer is how much my presence contributed to the discussion of capacity issues. Sitting here now I remember the Chair asking whether there were any cultural issues to consider in the work with the clients. Here it is worth noting that there were seven people in the room and only I and the Community Nurse (Asian) were minorities although I did not ask any of the professionals for their ethnicity. (Reflective Diary, 14 June 2011).

The two data extracts presented in this section suggest that my presence on some occasions led professionals, unprompted by me, to discuss or ask questions that may otherwise not have been the case. In one other instance however, a social worker set up a situation in which I would be a witness to her professional grievance. In this sense, rather than my utilising the professionals for my research ends, I was being used. The subsequent discussion that I present thus highlights the multi-faceted nature of ethics in my fieldwork.

The central character in the field notes below is Annika, one of the social workers who I developed a good working relationship with during fieldwork. On one shadowing session, she invited me to sit in on a meeting with her manager, Chris. As I entered the room Chris said something to the effect of 'this is to be anonymised' but I could not tell whether he was joking or not. It became clear to me that Annika invited me to the meeting to perform the role of witness to her complaints about unsustainable case loads. Chris, on the other hand, turned to management-speak and explained the various procedures that he had enacted to manage caseloads:

I had a premonition that it would be inappropriate to take notes and when we entered the room I sat at the far side of the table whilst Annika and Chris sat opposite each other with Chris closer to the door. It was one of the most uncomfortable and awkward experiences [in my life] because I wanted to be invisible but clearly I was not; I could not take notes, nor partake in the conversations but undeniably my presence was having an impact...Annika talked at length about the fact that [one] case had taken all her time. She implied that she was close to the edge but at the same time apologised for making this known to Chris because she felt that

‘everyone is in the same boat.’ Chris said that it was his role and that of the other managers to ensure that the social workers did not feel under such pressure and that Annika should bring this up with her supervisor. (Reflective Diary, 23 June 2011).

The data extract above draws attention to how ethical practice in research cannot be the sole responsibility of the researcher. My witnessing the discussion between Chris and Annikka was outside my control and moreover, an argument could be advanced that Annika set out to use me for her ends, which she had determined was the need for an ‘independent’ witness to her grievance about high caseloads. However Annika and Chris both appeared to interpret my presence as a signal to present their cases. On Annika’s part, her case was that all social workers were overworked – ‘everyone is in the same boat’ – and on Chris’ part, a denial of Annika’s point on the basis that management had put in place procedures for addressing high caseloads.

So my identities as a social worker and researcher played out in unexpected ways in Kotoka. Methodologically, being a social worker did not provide pointers for questions as I expected. However my skills as a social worker were useful as in the case of Annikka above when I had to empathise with her as she recounted stress accruing from her work load (Atkinson, 2004). Regarding my positioning as a researcher, professionals sometimes took me to be the ‘resident expert’, a depiction which occasionally led them to ‘perform’ for me. At other times, I was cast as an ‘independent’ witness and used as a sounding board: either to listen to professionals’ grievances within the team or about their high caseloads. In a similar way, my subjectivity as a black male of British nationality, played out in unexpected ways because my ethnicity was both visible and invisible in the research.

Operationalising ethnicity in fieldwork

In both Kotoka and Yarlow, ethnic differences played out in unforeseen but revealing ways. At Yarlow, my ethnicity as a black man was visible. Positioning myself as Ghanaian I used my heritage as a reference point for questions and answers about culture. Besides, all of Abrax's carers were of Black African origin, a good starting place for building rapport. Furthermore, during fieldwork my questions about how people's ethnicity affected their work with Abrax were critically engaged with openly. There was also no palpable sense of unease among the professionals when the subject of ethnicity was discussed. Arguably, professionals in Yarlow relished the prospect of discussing their ethnicity.

In contrast, professionals in Kotoka appeared uneasy about discussing ethnicity. As I have reported in Chapter Six, in Kotoka, professionals told me that they did not understand the concept of ethnicity or BME so, in the latter half of fieldwork, I asked about culture instead. But as a researcher, operationalising ethnicity as culture left me uneasy because, although the two concepts are inter-related, there are differences, in that the former captures a political and institutional phenomenon whereas the latter is more suitable for exploring everyday experiences. Furthermore, in my discussions with professionals I could perceive the disjuncture between academic and lay (everyday) understandings of ethnicity: as a researcher I thought of ethnicity as a fluid concept whereas my core participants in Kotoka spoke of it as if it were static. Another interesting reflection on my fieldwork was that, in Kotoka, I did not explicitly discuss participants' ethnic identities and instead, questions were framed around how the former contributed to their practice. In Yarlow, on the other

hand, I drew on insider perspectives to ask how Abrax's carers' culture impacted on their interpretation of his needs and hence the options that they presented to him.

Yet my application of insider perspectives in discussions with Abrax's carers revealed our different subjectivities, shattering my illusions about our shared commonalities. As a result, I was able to engage with some of the dynamics of the insider/outsider debate I explored in my methodological discussions in Chapter Three: sometimes even where the researcher considers themselves to be an insider, research participants may identify markers of difference of 'them' and 'me.' In my case, the cultural capital accruing from my education was a point of differentiation. During one life story interview with a Ugandan care worker, Robert (previously an accountant), I asked him to talk about his initial experiences of life in the UK. Robert recounted that accounting firms in London would not accept his Ugandan qualification. Eventually Robert found employment as a residential worker in Cambridge but this involved many hours commuting between London and Cambridge. Using my apparent British accent as a marker of difference between us, he suggested that whereas I would be accepted in the UK because of my accent, he wouldn't because he still sounded like a Ugandan. The realisation that Robert perceived my accent as a point of difference between us fractured my sense of shared commonality between us, fellow Africans. Altogether my fieldwork experiences mirror the warnings about the possibilities of reifying ethnic categories and conflating ethnicity with culture in empirical research that I discussed in Part One of the literature review (Chapter Two). In the next section I propose a model based on aspects of relational sociology as a potential solution to the problems of reification and conflation in empirical research on social categories.

Part Three. Ethnicity, learning disability, and mental capacity: towards a relational model

I argue in this section that one way to avoid conflation and reification of the three concepts central to my research is by operationalising them as relational concepts. My argument in this section is influenced primarily by ‘Manifesto for Relational Sociology’ (Emibayer, 1997). In relational sociology:

The very terms or units involved in a transaction [or relation] derive their meaning, significance, and identify from the (changing) functional roles they play in that transaction. The latter, seen as a dynamic, unfolding process, becomes the primary unit of analysis rather than the constituent elements themselves. (Emibayer, 1997; p287).

In the above conceptualisation, social categories – for example ethnicity, learning disability and mental capacity - are detectable from the outcomes of interactions within the networks that people inhabit. Social categories do not exist in and of themselves; instead, it is what people do and the choices that they make that produce outcomes identified as ethnic relations or learning disability or mental capacity. Thus culture is central to the discussion for two reasons. Culture symbolises agreed practices, shared meanings, social and moral frames of reference. Culture may also be seen as one of the mediums through which agency and structure interact: ‘The relation between culture and structure [in relational sociology] is not one of a duality between two autonomous entities. Rather, culture and structure, language and relational ties are

fused within a socio-cultural setting.’ (Mützel, 2009; p875). Consequently a relational model for my research would not deny the existence of the MCA or learning disability, for instance, because being social categories emanating from government policies, the two concepts can be conceived of as structure. In this latter sense, the two are by John Searle’s (1996) postulation ‘ontologically real.’ At the same time a relational model would escape any supposition that social categories are epistemologically ‘real’ or independent of human interpretations by drawing attention to situated meanings that arise within cultural contexts. Relational sociology implies that what is imposed at the macro level may not necessarily be actualised on the ground in peoples’ lives. This is because people will exercise agency by reinterpreting statutorily defined classifications. In so doing people are influenced by their values and socially accepted norms.

Because relational sociology stresses contextual networks rather than intrinsic qualities, it implies the need to clarify the relations that matter to individuals, as a way of making transparent the potentialities for the formation of social categories (Archer, 2010). In the context of professionals in Kotoka, the institution of integrated learning disability matters in their construction of social categories primarily because their actions are circumscribed by law. In this regard, it is arguably the case that professionals are more likely to draw upon statutory classifications of ethnicity, learning disability, and mental capacity. With Abrax we may conceive of him inhabiting deep and wide social relations. The wide relationships are broadly speaking society. On the other hand are Abrax’s deep social relations where he derives full meaning as a person. These deep relations involve his family and the private care company (including care workers), and it is here that he is likely to experience ethnic relations. How people in Abrax’s deep social network live, and their conceptions of

their ethnic identities matter more to his everyday life than his occasional interactions with professionals from Kotoka, although they too make decisions with far-reaching implications for Abrax.

By drawing on relational sociology one can argue that Abrax experiences ethnic relations notwithstanding that he does not communicate 'conventionally' and thus cannot self-identify. Abrax's network of carers who provide intimate help are all black men who, as I have demonstrated in Chapter Seven, do not call themselves British or Greek. Besides providing for his immediate needs Abrax's male carers, together with his family, also form his link to the external world. In interpreting his gestures and sounds people in his deep relations, such as family members and carers, arguably draw on their cultural frames of reference: 'Ethnic categories [or relations] shape institutional as well as informal cognition and recognition. They not only structure perception and interpretation in the ebb and flow of everyday interaction but channel conduct through official classifications and organisational routines.' (Brubaker, 2002; p184). For Abrax's carers who are not British, their work with him also influences their conceptions of their ethnic identity by opening up their consciousness to the British formalised way of providing care, and the everyday routines of a Greek extended family. Mirroring this, Abrax's ethnic identity is also impacted as he is introduced to non-European forms of socialisation and he is the target of actions drawn from his carers' interpretation of his needs through their (non-European) cultural frames of reference.

Through this transactional model, the discussion to date suggests that a relational approach provides potentially more useful conceptual tools to operationalise ethnicity (and social categories) in my research. Importantly, by drawing attention to context I avoid reification because a relational framework accommodates new

categories from each encounter between professionals and service users. In eschewing reification of ethnicity specifically, I also avoid a cause-and-effect analysis whereby culture is seen simplistically as the driver of decision-making between Abrax and his deep networks or between professionals in general. Rather, in the relational model, research participants draw on ethnic relations in particular circumstances when decisions have to be made or when specific encounters lead them to (re)negotiate their ethnic frameworks of reference as a way of arriving at decisions.

Furthermore, because the relational model suggests negotiation and contestation it draws attention to power in ethnic identity formation: 'Far from being an attribute or property of actors, then, power is unthinkable outside matrices of force relations; it emerges out of the very way in which figurations of relationships [...] are patterned and operate' (Emirbayer, 1997; p292). In the relational model all participants have power to affect the encounter (albeit it in different dimensions); as such, service users are not passive bearers of social categories, and through their actions they challenge classifications. Consequently service users' agency and subjectivity is notionally preserved and respected. A case in point is Dwayne, who I discussed in Chapter Six. Dwayne challenged his categorisation of mental health by psychiatrists by requesting a hearing at the Mental Health Tribunal against his sectioning. Furthermore through his actions, Dwayne resisted any attempts by professionals to categorise him as learning disabled or mentally (in)capable because he demonstrated clearly that he could choose.

Due to the constant re-figuration of relationships which arise from the contestation of power, a person's lived experience of social categories is in regular flux and is unstable (even if official classifications are static) because different spatio-temporal contexts require different negotiations and different outcomes. The further

implication of the above discussion is that everyone present at a given social gathering, where ethnic relations specifically are manifested, becomes affected by the encounter. Being the researcher I am part of the social relations through which ethnicity is constituted. Therefore, on the occasions that I observed Abrax or discussed culture with professionals in Kotoka, I interrogated my own ethnic identity through seeing new ethnic relations lived and demonstrated. In fieldwork, the questions that I asked participants about their culture, their thinking processes about the questions, and their thinking aloud about what they perceive their culture to be, similarly shaped them and me. Sometimes in answering my questions, participants have asked me about my culture presenting me with an opportunity to talk about my culture, which I may not have had. Therefore in fieldwork I have caused people to construct their ethnicity, and in so doing I have constructed mine (Andrade, 2000). Even in analysing the data I am the one who identified the markers of ethnicity, and argued through textual representation that those signs constituted ethnicity (Chaitin et al, 2009). The theoretical implication of this section is that the relational approach combines researcher identification and participant self-identification in operationalising ethnicity, which is arguably a more robust analytical framework.

Conclusion

In the preceding discussion I have reflected on the ethics and methodological impact of peoples' identities on my thesis. Abrax elicited ethical concerns before the research because being a learning disability service user, there were doubts around Abrax's mental capacity to consent, and whether he would be susceptible to coercion during fieldwork. Although I assessed Abrax as unable to understand my research, in fieldwork, he continuously surprised me with his level of understanding: often he

demonstrated a grasp of concepts which I considered complex but on other occasions he seemed unaware of some routine aspects of his life. Adopting an ethically robust position I always asked Abrax for his consent to observe him whenever I visited. An important ethical lesson I have gained from my experience with Abrax is that researchers should consider assessments of peoples' capacity to consent to participate in research as distinct from participants' understandings of their everyday lives. Moreover researchers should ensure a degree of social distance because they may not be able ascertain what research participants conceive of the social context of their engagement. This latter point especially applies in ethnographic research where the researcher becomes a part of participants' lives and their social networks. Given that the title 'researcher' is sometimes accepted as a mark of impartiality; one could easily garner trust and expectations which both may be unmet or abused. In my case, Abrax seemed unhappy whenever I rescheduled my visits leading me to wonder where he saw me as a researcher, friend, or professional.

Personally, in one sense, I was an 'insider' because as a social worker, PhD researcher, and a black man, I was engaged in fieldwork exploring ethnicity within statutory social services. I have shown in this chapter that my insider status played out in unexpected ways. If the benefits of being an insider include rapport building and acceptance by the group, then my experience in Kotoka suggests that achieving that status in fieldwork may not always be on the terms envisaged by the researcher. As such being an insider may not always hold methodological advantages. Furthermore the group involved in the research may position the researcher differently depending on the topic of discussion. For instance during my time in Yarlow, I consciously drew on my life experiences as a Ghanaian, firstly to build rapport, and secondly, to probe how the support workers' culture played out in their work with Abrax. Sometimes the

support workers granted me insider status such as when we talked about the experience of living in the UK as an African. However when we discussed their employment experiences of low-wages, their feelings of being over-qualified for their roles and powerless vis-à-vis their employer, they positioned me as an outsider. This is because in their view I enjoyed relatively more cultural capital from my status as a British citizen and high educational attainment. Thus insider status or a researcher's identity plays a multi-dimensional role in research. Researchers should reflect on whether they are actively seeking insider status or deploying their identities methodologically; what roles they are being ascribed or are seeking in the social relations of research, as well as the ethical implications of these positions.

CHAPTER NINE. CONCLUDING MY THESIS

In this thesis I have empirically examined how the social categories ethnicity, learning disability, and mental capacity are operationalised within statutory services, and how they manifest in the everyday life of a service user. Influenced by social constructionism, I firstly examined how professionals in Kotoka understood and articulated these social categories as they discharged their duties under the MCA. Then adopting a case study approach to gain breadth of understanding, I explored the embodiment of social categories in Abrax's life, and how his life story affirmed or refuted current understandings of these three social classifications.

My research interests arose out of an intellectual curiosity, professional and personal experiences, to think differently from current understandings of mental capacity, ethnicity, and learning disability. Currently the dominant understanding of mental capacity is that of a cognitive process underpinned by the conception of a rational individual whose autonomy needs to be protected or enhanced. It is also assumed that mental capacity can be assessed 'objectively' based on assessors' ratings of a person's understanding of the decision that they are being asked to make, whether they 'can retain, use and weigh up the information' (MCA Code of Practice, 2007) aligned to the task at hand at the time required; and finally, whether they can communicate the information. As evidenced by my literature review in Chapter Two, at present, very little is known about how the MCA's indicators of mental capacity operate on the ground although there is an increasing body of literature and case law. Moreover, while the definition of mental capacity in the MCA is drawn from medicine, law, and philosophy, careful cross-cultural anthropological work suggests

that in some societies, there is less emphasis on individualism (Bekker et al, 1999; Garro, 1998; White, 1998). Thus in some cultures families are an intrinsic part of decision-making, thereby drawing attention to the explanatory power of relational sociology as an alternative conception of mental capacity (as I outlined in the preceding chapter). With regards to research on ethnicity, in response to the postmodernist challenge, it is now accepted that ethnic classifications are neither static nor necessarily genetic. Given this consensus, the current methodological and substantive agenda is aimed at capturing the fluidity of ethnic categories in research design, as well as responding to the need to evidence how ethnic classifications contribute to inequality (Mir et al, 2012). Keeping to statutory services, since the post-war period, integration of services has been the longstanding aim of policymakers (Wistow, 2012), yet there is little empirical research on professional practice within integrated learning disability teams and how these affect the realisation of policy aims. I have responded to these latterly cited challenges in my thesis through my adoption of ethnography, and my fieldwork choice of statutory services - 'sites of power' - (Rose, 1996) – where categorisations and resource allocation occur.

I chose ethnography because of methodological flexibility and its fit with my paradigmatic affiliations to induction and social constructionism. As I demonstrated in the literature review chapter, the MCA is a complex piece of legislation and substantive research agendas are still emerging; consequently, I wanted a methodology which would orientate my fieldwork towards what seemed salient to research participants. Epistemologically, I was interested in the localised meanings that research participants and their social networks adopted with respect to the three social categories, and the practices that sustained these understandings. Thus epistemologically and methodologically, my research is an innovative addition to the

mental capacity literature, which often is drawn to quantitative methods, and is epistemologically inclined towards realism. My methodological approach has enabled me to uncover some new understandings in the operationalisation of the MCA. In my data analyses (Chapters Six – Eight), adopting thick description, I have presented detailed data on organisational context as well as the emotions and intentions of research participants (Ponterotto, 2006). Whereas the MCA assumes that mental capacity can be assessed ‘objectively’ my empirical research shows that contextual factors impact on whether professionals will assess capacity in the first place.

Addressing research questions

I set out to address five questions in my thesis:

1. In terms of the internal composition of an integrated learning disability service and how its structure impacts on the discharge of duties under the MCA; who makes decisions about which duties to discharge?
2. The literature review showed that risk is a prime concern of statutory services: how does this relate to the MCA? What understandings of risk are propagated by professionals and service users?
3. How do professionals articulate the concept of ethnicity and how does this shape their practice decisions?
4. From service users’ viewpoints, what are the impacts of professional decisions-making arising from their conception of ethnicity?
5. Lastly, how are all these substantive concerns manifested in the lives of service users?

Question 1 above is principally about the impact of context. Kotoka may be seen as a more complicated context than Yarlow. At the time of my fieldwork there appeared to be three distinct policies being implemented: safeguarding, personalisation, and the MCA. Implementing personalisation and safeguarding policies seemed to be the organisational imperatives but the MCA underpinned these policies both formally and informally (as I showed in Chapter Five with my description of the work of the PCP Coordinator). Thus, in contrast to the informal work processes that I described in Chapter Five, there were formalised procedures around personalisation and safeguarding referrals. Each had identifiable personnel. As I have described in Chapters Five and Six, the administrator for personalisation sat opposite the head of social work on the first floor and the Safeguarding Team were in charge of safeguarding policy. Besides discharging multiple duties under different strands of legislation, professionals in Kotoka were also engaged in delineating their roles vis-à-vis the wider local authority. By contrast, as I have described in Chapter Seven, care workers at Abrax's home in Yarlow saw their primary aim as promoting Abrax's choice.

Apart from organisational policy imperatives, another important contextual difference between Kotoka and Yarlow was in their respective hierarchical structures, and consequently, how power was manifested. In Abrax's home (Yarlow) all the professionals had the same rank as care workers and all of them were black. Although the care workers claimed that Abrax made his own decisions, I observed that they had subtle ways of enforcing their wishes. Sometimes they even forced him to eat against his will. In Kotoka, by contrast, there were different levels of seniority. Furthermore, although I did not observe any conflict between the different professions, those from 'health' seemed on top of the hierarchy. Also, as I have shown in Chapters Five and

Six, within certain spaces and around specific issues some key individuals' views dominated. Thus in CCP²³ for instance three white men drawn from 'health', in more senior positions tended to direct discussions about risks including how the organisation should handle service users' consent to any proposed care packages. In this way, gender and ethnicity linked into organisational hierarchy and power as key dimensions of context in the operationalisation of mental capacity.

With regards to risk (question 2), safeguarding issues arose from professionals' notion of risks. Issues of risk included the following: mental health, 'vulnerability', sexual practices, domestic violence, 'organisational' issues whereby a service user reported that a member of staff behaved in a way that has put them at risk, financial or physical abuse. Sometimes professionals constructed risk and this was different from a safeguarding episode because the latter was a more formal process with set statutory procedures and accompanying timescales. Professionals also reconceptualised safeguarding into whether the issue was of such a nature as to be dealt by the police or by another team within the local authority. In safeguarding, capacity assessments were conducted to determine whether the service user understood the safeguarding process, or whether they understood the nature of the risks to which they were exposing themselves. Where service users were found to have capacity, this presented particular difficulties for the service because it threw professionals sharply into the care/control dilemma which statutory services face. If service users demonstrated capacity, then practitioners evaluated the quality of their decisions. Thus, even if service users showed mental capacity, practitioners (and families) assessed whether they engaged in 'risky' behaviour such as sexual promiscuity. Thus in practice, faced with a statutory duty to 'protect' service users,

²³ Complex Cases Panel

professionals could not adhere to the MCA's 'unwise decision' principle. Consequently with Safeguarding Adults, where service users manifested capacity, professionals sometimes conceptualised their duties as 'policing risk exposure'.

Through questions 3 and 4, broadly, I explored how street level bureaucrats' decisions were affected by their ethnic identities or the classifications that they assigned to service users. In the various empirical chapters, I showed that in the main, professionals struggled to articulate the concept of ethnicity, at least in a way that satisfactorily reflected the meanings of ethnicity propagated by sociologists. Instead most professionals took ethnicity to mean culture, and this was also the case with Abrax's carers. I have also presented data in the thesis which evidences that culture was operationalised as the property of the Other. For social work, which is committed to anti-oppressive practice, the finding of my thesis that there was a close relationship between ethnic identification and risk categorisation is a challenge to the value base of the profession. I witnessed on my research site in the integrated team that the most 'complex' cases tended to involve people described as ethnic minorities.

Abrax's life story, which I narrated in Chapter Six as a response to research question 5, highlights the confluence of structure and agency in the embodiment of social categories. At primary school Abrax acquired the classification 'learning disability' through the education system at his parents' request. Although the prevailing view is that learning disability is a diagnostic category, embodied usually at birth (DOH, 2001), and identified by doctors (NHS Choices, 2013), it is instructive that Abrax's condition had not been medically identified notwithstanding his regular examination at GOSH. Abrax's life may also be said to show that context matters in the manifestation and operationalisation of social categories. In Yarlow ethnicity was a lived classification: care workers cooked Greek food for Abrax, Abrax's family

visited regularly and spoke to him in Greek, and he was immersed in Greek traditions such as celebrating the birthday of the saint he was named after. Furthermore whilst Abrax's carers told me that he could make his own decisions, he had not been assessed under the MCA. Moreover when his care workers made decisions for him, they assumed that they were doing so in his 'best interest.' In this way, it may be argued that Abrax's life in Yarlow shows that in routine social relations people make decisions for each other on the underlying assumption that best interests have been taken into account. The MCA formalised this supposition of everyday interaction; in statutory contexts professionals are now mandated to engage in the procedural action of eliciting best interest. In effect the MCA requires professionals to act differently from how they are socialised.

The one question that I could not fully address in my fieldwork was whether the MCA was implemented wholly or discretely. This suggests the methodological limitation of my study. In my fieldwork, taking inspiration from some of the ethnography literature, I did not have any prior questions. Instead, I orientated my research as I became familiar with the fieldwork site and pertinent issues. This was advantageous in one sense because it allowed me to gain understanding of complexity. Yet this was also a drawback given that I was a PhD student without unlimited time to conduct fieldwork. As it happened, the MCA was complex, with several strands straddling different departments and teams within the local authority. In future research on the MCA, whether a deductive or inductive approach is taken (for example, grounded theory) researchers would need to pilot the study site to understand the context better, and concomitantly how best the research questions could be addressed.

My thesis has contributed significant knowledge in my substantive areas. On the sociology literature on ethnicity, I have provided further evidence on how social categorisations impact on the distribution of State resources. With respect to learning disability, theoretically and empirically, I have also generated new understandings of how agencies respond to people classified as learning disabled. Finally, with mental capacity, there have been very few sociological writings on the subject therefore my thesis charts a new research agenda. As I have demonstrated in the preceding chapters, the current research agenda in mental capacity aims to evidence decision-making capacity in categories of people – for example, older people, people with mental health issues, and learning disabled people. But few of these studies pay attention to context. However, as I have shown in my thesis, institutional configuration matters, because it determines how statutory duties are met and who has power to do what. Besides, the life experiences and values of assessors are significant: for instance some professionals may consider sexual relations as akin to morality and would thus operationalise a high threshold of mental capacity. If context is a key dimension of how the MCA is operationalised, then my thesis charts a new research agenda. By employing qualitative methodology I have shown convincingly that whether formally or informally, mental capacity assessments involve complex interactions of life history, professional knowledge, institutional arrangements, culture, and emotion.

REFERENCES

ABBOTT, A., 1997. Of Time and Space: The Contemporary Relevance of the Chicago School. *Social Forces*, **75**(4), pp. 1149-1182.

ADAMS, R., DOMINELLI, L. and PAYNE, M., 2002. *Social Work: Themes, Issues and Critical debates*. 2 edn. Basingstoke: Palgrave Macmillan.

ADSS, 2005. '*Safeguarding Adults*'. London: Association of Directors of Social Services.

AGUILAR, J. L., 1981. Insider research: An Ethnography of a Debate. In: D. MESSERSCHMIDT, ed, *Anthropologists at Home in North America*. Cambridge: Cambridge University Press, pp. 15-26

ALEXANDER, C., 2006. Introduction: Mapping the issues. *Ethnic and Racial Studies* (Special Issue '*Writing Race: Ethnography and Difference*'), **29**(3), pp. 397-410.

ALEXANDER, J. C., 1996. Cultural Sociology or Sociology of Culture? Towards a Strong Program. *Culture*, **10**(3-4), pp. 1-5.

AMIT-TALAI, V., 2000. Introduction: Constructing the Field. In: V. AMIT-TALIA, ed, *Constructing the Field: Ethnographic Fieldwork in the Contemporary World*. London: Routledge, pp. 1-18.

ANGROSINO, M., 2008. *Doing Ethnographic and Observational Research*. Los Angeles: Sage.

ANGROSINO, M. V. and DE PEREZ, KIMBERELY., 2000. Rethinking Observation: From Method to Context. In: N.K. DENZIN and Y.S. LINCOLN, eds,

Handbook of Qualitative Research. 2 edn. Thousand Oaks, Calif.: Sage Publications, pp. 673-702.

ANONYMOUS. Undated. *Local Implementation Plan*.

ANONYMOUS. 2010. *Board Report: Review of Learning Disabilities Section 75 Agreement*.

ANTAKI, C., FINLAY, W. M. L. and WALTON, C., 2009. Choices for People With Intellectual Disabilities: Official Discourse and Everyday Practice. *Journal of Policy and Practice in Intellectual Disabilities*, **6**(4), pp. 260-266.

APPELBAUM, B. C., APPELBAUM, P. S. and GRISSO, T. M. D., 1998. Competence to Consent to Voluntary Psychiatric Hospitalization: A Test of a Standard Proposed by American Psychiatric Association. *Psychiatric Services*, **49**(9), pp. 1193-1196.

APPELBAUM, P., 2010. Consent in Impaired Populations. *Current Neurology and Neuroscience Reports*, **10**(5), pp. 363-373.

APPELBAUM, P. S., 1998. Ought We to Require Emotional Capacity as Part of Decisional Competence? *Kennedy Institute of Ethics Journal*, **8**(4), pp. 377-387.

APPELBAUM, P. S., 2007. Assessment of Patients' Competence to Consent to Treatment. *New England Journal of Medicine*, **357**(18), pp. 1834-1840.

APPELBAUM, P.S. and GRISSO, T., 1995. The MacArthur Treatment Competence Study. I: Mental Illness and Competence to Consent to Treatment. *Law and Human Behavior*, **19**(2), pp. 105-126.

APPLETON, S., 2009, Integration and learning disability

http://www.dhcarenetworks.org.uk/library/Resources/ICN/ICN_advice/ICN_FINAL_Integration_and_learning_disability2.pdf [accessed March 07, 2013].

ARCHER, L., 2011. Constructing Minority Ethnic Middle-class Identity: An Exploratory Study with Parents, Pupils and Young Professionals. *Sociology*, **45**(1), pp. 134-151.

ARCHER, M., 2010. Critical Realism and Relational Sociology: Complementarity and Synergy. *Journal of Critical Realism*, **9**(2), pp. 199-207.

ARSCOTT, K., DAGNAN, D. and KROESE, S. B., 1999. Assessing the Ability of People with a Learning Disability to Give Consent to Treatment. *Psychological Medicine*, **29**(6), pp. 1367-1375.

ASPINALL, P. J., 2012. Answer Formats in British Census and Survey Ethnicity Questions: Does Open Response Better Capture 'Superdiversity'? *Sociology*, **46**(2), pp. 354-364.

ASPINALL, P. J., 2002. Collective Terminology to Describe the Minority Ethnic Population: The Persistence of Confusion and Ambiguity in Usage. *Sociology*, **36**(4), pp. 803-816.

ASPINALL, P. J., 2001. Operationalising the Collection of Ethnicity Data in studies of the sociology of health and illness. *Sociology of Health and Illness*, **23**(6), pp. 829-862.

ATKINSON, D., 2004. Research and Empowerment: Involving People with Learning Difficulties in Oral and Life History Research. *Disability and Society*, **19**(7), pp. 671-702.

ATKINSON, D., 1985. The Use of Participant Observation and Respondent Diaries in a Study of Ordinary Living. *British Journal of Mental Subnormality*, **Part 1**(Number 60), pp. 33-40.

ATKINSON, D., 2005. Research as Social Work: Participatory Research in Learning Disability. *British Journal of Social Work*, **35**(4), pp. 425-434.

ATKINSON, P., 2006. Rescuing Autoethnography. *Journal of Contemporary Ethnography*, **35**(4), pp. 400-404.

ATKINSON, P., 1990. *The Ethnographical Imagination*. London: Routledge.

ATKINSON, P., COFFEY, A., DELAMONT, S., et al., 2001 (reprinted 2008). Editorial Introduction. In: P. ATKINSON, A. COFFEY, S. DELAMONT, J. et al, eds, *Handbook of Ethnography*. London: Sage Publications, pp. 1-7.

ATKINSON, D., JACKSON, M. and WALMSLEY, J. 1997. *Forgotten Lives: Exploring the History of Learning Disability*. Kidderminster: British Institute of Learning Disabilities.

BAILEY, D. and LIYANAGE, L., 2012. The Role of the Mental Health Social Worker: Political Pawns in the Reconfiguration of Adult Health and Social Care. *British Journal of Social Work*, **42**(6), pp. 1113-1131.

BANTON, J., 2005. Historical and Contemporary Modes of Racialization. In: K. MURJI and J. SOLOMOS, eds, *Racialization: Studies in Theory and Practice*. Oxford: Oxford University Press, pp. 51-68.

BANTON, M., 2011. A Theory of Social Categories. *Sociology*, **45**(2), pp. 187-201.

BARBOUR, R., 2001. Checklists for Improving Rigour in Qualitative Research: a Case of the Tail Wagging the Dog? *British Medical Journal*, **322**, pp. 1115-1117.

BARNES, C., 2003. What a Difference a Decade Makes: Reflections on Doing 'Emancipatory' Disability Research. *Disability and Society*, **18**(1), pp. 3-17.

BARRETT, R., 1996. *The Psychiatric Team and the Social Definition of Schizophrenia: An Anthropological Study of Person and Illness*. Cambridge: Cambridge University Press.

BARRON, A. H. and BANES, J., 2004. Offenders with Intellectual Disability: A Prospective Comparative Study. *Journal of Intellectual Disability Research*, **48**(1), pp. 69-71.

BARRON, K., 2002. Who am I? Women with Learning Difficulties (re)constructing their Self-identity. *Scandinavian Journal of Disability Research*, **4**(1), pp. 58-79.

BEADLE-BROWN, J., MANSELL, J. and KOZMA, A., 2007. Deinstitutionalization in Intellectual Disabilities. *Current Opinion in Psychiatry*, **20**(5), pp. 437-442.

BECKER, H. S., 2009. How to Find Out How to Do Qualitative Research. Available: <http://home.earthlink.net/~hsbecker/articles/NSF.html>. [accessed June 26, 2013]

BECKFORD, M., 2012. Judge Attacks Forced Marriage that Put Disabled Woman 'at risk'. *The Daily Telegraph*.

BEKKER, H., LILLEYMAN, J., THORNTON, J. G., et al., 1999. Informed Decision Making: an Annotated Bibliography and Systematic Review. *Health Technology Assessment*, **3**(1), pp. 1-156.

BERGHMANS, R., DICKENSON, D. and MEULEN, T. R., 2004. Mental Capacity: In Search of Alternative Perspectives. *Health Care Analysis (Special issue 'Mental Capacity: In Search of Alternative Perspectives')*, **12**(4), pp. 251-263.

BISWAS, A. and BHAUMIK, S., 2003. Learning Disabilities and Ethnicity. *Advances in Psychiatric Treatment*, **9**(3), pp. 174-176.

BLACKMAN, S. J., 2007. 'Hidden Ethnography': Crossing Emotional Borders in Qualitative Accounts of Young People's Lives. *Sociology*, **41**(4), pp. 699-716.

BOND, R. J. and HURST, J., 2010. How Adults with Learning Disabilities View Living Independently. *British Journal of Learning Disabilities*, **38**(4), pp. 286-292.

BOOTH, T. and BOOTH, W., 1996. Sounds of Silence: Narrative Research with Inarticulate Subjects. *Disability and Society*, **11**(1), pp. 55-69.

BRADBY, H., 2003. Describing Ethnicity in Health Research. *Ethnicity and Health*, **8**(1), pp. 5-13.

BRANDON, M., BELDERSON, P., WARREN, C., et al., 2008. *Analysing Child Deaths and Serious Injury through Abuse and Neglect: What Can We Learn? A*

- Biennial Analysis of Serious Case Reviews 2003-5*. Department for Children, Schools and Families, Research Report DCSF-RR023.
- BREDEN, T. M. and VOLMANN, J., 2004. The Cognitive Based Approach of Capacity Assessment in Psychiatry: A Philosophical Critique of the Macaw-T. *Health Care Analysis (Special issue 'Mental Capacity: In Search of Alternative Perspectives')*, **12**(4), pp. 273-283.
- BREUER, FRANZ., MRUCK, KATJA. AND ROTH, WOLFF-MICHAEL., 2002. Subjectivity and Reflexivity: An Introduction. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, **3**(3), Art. 9, <http://nbn-resolving.de/urn:nbn:de:0114-fqs020393>.
- BROADHURST, K., WASTELL, D., WHITE, S., et al., 2010. Performing 'Initial Assessment': Identifying the Latent Conditions for Error at the Front-Door of Local Authority Children's Services. *British Journal of Social Work*, **40**(2), pp. 352-370.
- BROWN, K., 2011. 'Vulnerability': Handle with Care. *Ethics and Social Welfare*, **5**(3), pp. 313-321.
- BROWN, K. D., 2011. Elevating the Role of Race in Ethnographic Research: Navigating Race Relations in the Field. *Ethnography and Education*, **6**(1), pp. 97-111.
- BROWN, A. P., 2008. A Review of the Literature on Case Study Research. *Canadian Journal for New Scholars in Education*, **1**(1), pp. 1-13.
- BROWN, R. and BARBER, P., 2008. *The Social Worker's Guide to the Mental Capacity Act 2005*. Exeter: Learning Matters.

- BRUBAKER, R., 2002. Ethnicity Without Groups. *European Journal of Sociology*, **43**(02), pp. 163-189
- BRYMAN, A., 2008. *Social Research Methods*. 3 edn. Oxford: Oxford University Press.
- BUCHANAN, A., 2004. Mental Capacity, Legal Competence and Consent to Treatment. *Journal of the Royal Society of Medicine*, **97**(9), pp. 415-420.
- BUCHANAN, I., (2013). Social Work Practice and Learning Disability. In: M. DAVIES, ed, *The Blackwell Companion to Social Work*. Fourth Edition edn. Oxford: Blackwells, pp. 283-290.
- BUCHANAN, I., 2011. Policy Swings and Roundabouts: Social Work in Shifting Social and Economic Contexts. In: J. SEDEN, S. MATHEWS, M. MCCORMICK et al, eds, *Professional Development in Social Work*. Abingdon: Routledge, pp. 10-16.
- BUCHANAN, I. and WALMSLEY, J., 2006. Self-Advocacy in Historical Perspective. *British Journal of Learning Disabilities*, **34**(3), pp. 133-138.
- CALCRAFT, R., 2007. Blowing the Whistle on Abuse of Adults with Learning Disabilities. *Journal Of Adult Protection*, **9**(2), pp. 15-30.
- CAMBRIDGE, P., 2008. The Case for a New 'Case' Management in Services for People with Learning Disabilities. *British Journal of Social Work*, **38**(1), pp. 91-116.
- CAMBRIDGE, P., FORRESTER-JONES, R., CARPENTER, J., et al., 2005. The State of Care Management in Learning Disability and Mental Health Services 12 Years after Care Management. *British Journal of Social Work*, **35**(7), pp. 1039-1062.

- CAMERON, A., LART, R., BOSTOCK, L., et al., 2012. *Factors that Promote and Hinder Joint and Integrated Working Between Health and Social Care Services*. London: Social Care Institute for Excellence.
- CANDEA, M., 2009. Arbitrary Locations: In Defence of the Bounded Field-site. In: M. FALZON, ed, *Multi-Sited Ethnography: Theory, Praxis and Locality in Contemporary Social Research*. Surrey: Ashgate, pp. 25-45.
- CARNEY, T., 1997. Competence. *International Journal of Law and Psychiatry*, **20**(1), pp. 1-4.
- CARSON, D., 1993. Disabling Progress: The Law Commission's Proposals on Mentally Incapacitated Adults' Decision-making. *Journal of Social Welfare and Family Law*, **15**(3), pp. 304-320.
- CARTER, B. and DYSON, S. M., 2011. Territory, Ancestry and Descent: The Politics of Sickle Cell Disease. *Sociology*, **45**(6), pp. 963-976.
- CARTER, B. and FENTON, S., 2010. Not Thinking Ethnicity: A Critique of the Ethnicity Paradigm in an Over-Ethnicised Sociology. *Journal for the Theory of Social Behaviour*, **40**(1), pp. 1-18.
- CASPER, M. J. and TALLEY, L. H., 2005. Preface. *Journal of Contemporary Ethnography (Special Issue 'Ethnography and Disability Studies')*, **34**(2), pp. 115-120
- CASPER, M. J. and MOORE, J. L., 2009. *Missing Bodies*. New York: New York University Press.

CATTARINICH, X., GIBSON, N. and CAVE, A. J., 2001. Assessing Mental Capacity in Canadian Aboriginal Seniors. *Social Science and Medicine*, **53**(11), pp. 1469-1479.

CAUGHEY, J. L., 2006. *Negotiating Cultures and Identities: Life History Issues, Methods, and Readings*. Lincoln: University of Nebraska Press.

CHAITIN, J., LINSTROTH, J. P. and HILLER, P. T., 2009. Ethnicity and Belonging: An Overview of a Study of Cuban, Haitian and Guatemalan Immigrants to Florida. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, **3**(3), Art. 12, <http://nbnresolving.de/urn:nbn:de:0114-fqs0903122>.

CHARLAND, L., 2011 Decision-Making Capacity.

<http://plato.stanford.edu/entries/decision-capacity/> [accessed April 19, 2011].

CHARLAND, L. C., 2001. Mental Competence and Value: The Problem of Normativity in the Assessment of Decision-making Capacity. *Psychiatry, Psychology and Law*, **8**(2), pp. 135-145.

CHARLAND, L. C., 1998. Appreciation and Emotion: Theoretical Reflections on the MacArthur Treatment Competence Study. *Kennedy Institute of Ethics Journal*, **8**(4), pp. 359-376.

CHARMAZ, K., 2000. Grounded Theory: Objectivist and Constructivist Methods. In: N. DENZIN K. and Y. LINCOLN S., eds, *Handbook of Qualitative Research*. 2nd edn. London: Sage Publications, pp. 509-535.

CHARMAZ, K. and MITCHELL, R. G., 2001. Grounded Theory in Ethnography. In: P. ATKINSON, A. COFFEY, S. DELAMONT, et al., eds, *Handbook of Ethnography*. London: Sage Publications, pp. 160-174.

CHARMAZ, K., 2006. *Constructing Grounded Theory: a Practical Guide Through Qualitative Analysis*. London: Sage Publications.

CLARKE, A. E., 2003. Situational Analyses: Grounded Theory Mapping After the Postmodern Turn. *Symbolic Interaction*, **26**(4), pp. 553-576.

CLAWSON, R. and VALLANCE, P., 2010. *Forced Marriage and Learning Disabilities: Multi-Agency Practice Guidelines*. HM Government.

CLEMENTS, N., CLAPTON, J. and CHENOWETH, L., 2010. Indigenous Australians and Impaired Decision-Making Capacity. *Australian Journal of Social Issues*, **45**(3), pp. 383-393.

CODE, L., Autonomy, Incredulity, and the Epistemology of Testimony, *Was Autonomy the Wrong Ideal? Conference (London, Senate House)*. 30 September - 1 October 2011.

COLE, M., 1993. 'Black and Ethnic Minority' or 'Asian, Black and Other Minority Ethnic': A Further Note on Nomenclature. *Sociology*, **27**(4), pp. 671-673.

CORBIN, J. and STRAUSS, A., 1990. Grounded Theory Research: Procedures, Canons, and Evaluative Criteria. *Qualitative Sociology*, **13**(1), pp. 3-21.

CORTAZZI, M., 2001 (reprinted 2008). Narrative Analysis in Ethnography. In: P. ATKINSON, A. COFFEY, S. DELAMONT, eds, *Handbook of Ethnography*. London: Sage Publications, pp. 384-394

DABYDEEN, D., GILMORE, J. and JONES, C., 2010. *The Oxford companion to Black British History*. Oxford: Oxford University Press.

DAVEY, B., LEVIN, E., ILIFFE, S. et al., 2005. Integrating Health and Social Care: Implications for Joint Working and Community Care Outcomes for Older People. *Journal of Interprofessional Care*, **19**(1), pp. 22-34.

DAVIES, K., COLLERTON, J. C., JAGGER, C., et al., 2010. Engaging the Oldest Old in Research: Lessons from the Newcastle 85+ study. *BMC Geriatrics*, **10**(64), pp. 2-9.

D'CRUZ, H., GILLINGHAM, P. and MELENDEZ, S., 2007. Reflexivity, its Meanings and Relevance to Social Work: A Critical Review of the Literature. *British Journal of Social Work*, **37**(1), pp. 73-90.

DELANTY, G., 1997. *Social science: Beyond Constructivism and Realism*. Buckingham: Open University Press.

DENZIN, N. and LINCOLN, Y., 2003. The Discipline and Practice of Qualitative Research In: N. DENZIN and Y. LINCOLN, eds, *Strategies of Qualitative Enquiry*. 3edn. London: Sage, pp. 1-44.

DENZIN, N. K., 2002. Confronting Ethnography's Crisis of Representation. *Journal of Contemporary Ethnography*, **31**(4), pp. 482-490.

DENZIN, N. K., 1997. *Interpretive Ethnography: Ethnographic Practices for the 21st century*. Thousand Oaks, CA: Sage.

DENZIN, N. K. and LINCOLN, Y. S., 2003. Introduction: The Discipline and Practice of Qualitative Research. In: N. K. DENZIN. and Y. S. LINCOLN, ed, *The Landscape of Qualitative Research: Theories and Issues*. 2 edn. Thousand Oaks: Sage, pp. 1-45.

DEPARTMENT FOR CONSTITUTIONAL AFFAIRS, 2007. *Mental Capacity Act 2005 Code of Practice*. Guidance edn. London: TSO

DEPARTMENT OF HEALTH, 2002. *Supported Housing and Care Homes: Guidance on Regulation*

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008905. [accessed July 3, 2013] .

DEPARTMENT OF HEALTH, 2012. *Transforming care: A national response to Winterbourne View Hospital*.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127310/final-report.pdf.pdf: [accessed July 3, 2013].

DEPARTMENT OF HEALTH, 2009. The Mental Capacity Act - Factsheet for Social Scientists <http://www.screc.org.uk/files/mcafactsheet.pdf> [accessed June 3, 2013].

DEPARTMENT OF HEALTH, 2009. *Report on the Consultation: The Review of No Secrets Guidance*. London.

DEPARTMENT OF HEALTH, 2003. *Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care*. London.

DEPARTMENT OF HEALTH, 2001. *Valuing People: A New Strategy for the 21st Century*. London

DEPARTMENT OF HEALTH, 2000. *The NHS Plan*. Norwich: HMSO.

DEPARTMENT OF HEALTH, 2000. *No Secrets: Guidance on Developing and Implementing Multi-agency Policy and Procedures to Protect Vulnerable Adults*. London.

DEPARTMENT OF HEALTH AND HOUSING OPTIONS, 2010. Planning and Commissioning Housing for People with Learning Disabilities - A Toolkit for Local Authorities

<http://www.housinglin.org.uk/Topics/browse/HousingLearningDisabilities/ValuingPeople/?parent=6072&child=8010> [accessed April 17, 2012].

DEPARTMENT OF HEALTH SCIENTIFIC DEVELOPMENT AND BIOETHICS DIVISION, 2008. *Guidance on Nominating a Consultee for Research Involving Adults who Lack Capacity to Consent*.

DEPARTMENT OF HEALTH, 2010. *Prioritising Need in the Context of Putting People First: a Whole System Approach to Eligibility for Social Care - Guidance on Eligibility Criteria for Adult Social Care*

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113155.pdf [accessed July 3, 2013].

DEPARTMENT OF HEALTH/CHILD HEALTH AND MATERNITY SERVICES
BRANCH, 2006. *Transition: Getting it Right for Young People*. London

DEVAULT, M. L. and MCCOY, L., 2002. Institutional Ethnography: Using Interviews to Investigate Ruling Relations. In: J. F. GUBRIUM and J. A. HOLSTEIN, eds, *Handbook of Interview Research: Context and Method*. Thousand Oaks: Sage, pp. 751-776.

DEWALT, K. M., DEWALT, B. R. and WAYLAND, C. B., 1998. Participant Observation. In: H. R. BERNARD, ed, *Handbook of methods in cultural anthropology*. Walnut Creek, CA: Sage, pp. 259-299.

DISTRICT JUDGE GORDON ASHTON., 2012. Mental Capacity and the Law - Past, Present and Future, *Capacity Assessment: Ethical, Political and Metaphysical Issues Conference (Essex, University of Essex)*, 20 May 2012.

DIXON-WOODS, M. and ANGELL, E. L., 2009. Research Involving Adults who Lack Capacity: How Have Research Ethics Committees Interpreted the Requirements? *Journal of Medical Ethics*, **35**(6), pp. 377-381.

DOBSON, C., 2008. *Conducting Research with People not Having the Capacity to Consent to their Participation*. Leicester: The British Psychological Society.

DOUGLAS, M., 1992 (reprinted 1996). *Risk and Blame*. London: Routledge.

DOUGLAS, M., 1985. *Risk Acceptability According to the Social Sciences*. London: Russell Sage Foundation.

DOWSE, L., 2001. Contesting Practices, Challenging Codes: Self Advocacy, Disability Politics and the Social Model. *Disability and Society*, **16**(1), pp. 123-141.

DUFFY, S. and GILLESPIE, J., 2009. Personalisation and Safeguarding <http://www.incontrol.org.uk/media/52833/personalisation%20safeguarding%20discussion%20paper%20version%201.0.pdf> [accessed April 28, 2012].

DUFFY, S., WATERS, J. and GLASBY, J., 2010. *Personalisation and the Social Care Revolution*. University of Birmingham: Health Services Management Centre.

DUNN, L. B., NOWRANGI, M., PALMER, B. W., et al., 2006. Assessing Decisional Capacity for Clinical Research or Treatment: A Review of Instruments. *American Journal of Psychiatry*, **163**(8), pp. 1323-1334.

DUNN, M. C., CLARE, I. C. H. and HOLLAND, A. J., 2008. Substitute Decision-Making for Adults with Intellectual Disabilities Living in Residential Care: Learning Through Experience. *Health Care Analysis*, **16**(1), pp. 234-253.

DUNN, M., CLARE I. C. H. and HOLLAND A. J., 2010. 'Living a Life Like Ours': Support Workers' Accounts of Substitute Decision-making in Residential Care Homes for People with Intellectual Disabilities'. *Journal of Intellectual Disability Research*, **54**(2), pp. 144-160.

DUNN, M., CLARE, I. C. H., HOLLAND., 2007. Constructing and Reconstructing 'Best Interests': An Interpretative Examination of Substitute Decision-making under the Mental Capacity Act 2005. *Journal of Social Welfare and Family Law*, **29**(2), pp. 117-132.

DUNN, M. C., CLARE, I. C. H. and HOLLAND, A. J., 2008. To Empower or to Protect? Constructing the 'Vulnerable Adult' in English Law and Public Policy. *Legal Studies*, **28**(2), pp. 234-253.

DWYER, S., 2009. The Deprivation of Liberty Safeguards and People with Dementia: Implications for Social Workers. *British Journal of Social Work*, pp. 1-14.

DYE, L., HARE, D. J. and HENDY, S., 2007. Capacity of People with Intellectual Disabilities to Consent to Take Part in a Research Study. *Journal of Applied Research in Intellectual Disabilities*, **20**(2), pp. 168-174.

EDGERTON, R., 1993. *The Cloak of Competence*. Berkeley: University of California Press.

EDGERTON, R. B., 1984. The Participant-Observer Approach to Research in Mental Retardation. *American Journal of Mental Deficiency*, **88**(5), pp. 498-505.

EDWARDRAJ, S., MUMTAJ, K., PRASAD, J. H., et al., 2010. Perceptions About Intellectual Disability: A Qualitative Study from Vellore, South India. *Journal of Intellectual Disability Research*, **54**(8), pp. 736-748.

ELDER-VASS, D., 2012. *The Reality of Social Construction*. Cambridge: Cambridge University Press.

ELLIOTT, E. D., 1983. *Risk and Culture: An Essay on the Selection of Technical and Environmental Dangers*. Yale Law School. Faculty Scholarship Series. Paper 2192.

ELLIS, K., 2004. Promoting Rights or Avoiding Litigation: The Introduction of the 1998 Human Rights Act into Adult Social Care in England. *European Journal of Social Work*, 7(3), pp. 321-340.

ELLISON, G., From Pitfalls to Principles: Conducting Applied Social Research on Ethnic Inequalities, *Exploring Ethnic Diversity in UK Social Research Conference (Sheffield, University of Sheffield)*, 14 April 2010.

EMERSON, R. M., 1995. *Writing Ethnographic Field notes*.

<http://www.pacificdiscovery.org/credit/SEAreadings/Robert%20et.al.%20-%20Writing%20Ethnographic%20Fieldnotes.pdf>: [accessed July 1, 2013]

EMERSON, R. M., FRETZ, R. I., SHAW, L. L., 2001 (reprinted 2008). Participant Observation and Field notes. In: P. ATKINSON, A. COFFEY, S. DELAMONT, et al, eds, *Handbook of Ethnography*. London: Sage, pp. 352-368.

EMIRBAYER, M., 1997. Manifesto for a Relational Sociology. *American Journal of Sociology*, 103(2), pp. 281-317.

EVANS, T., 2012. Organisational Rules and Discretion in Adult Social Work. *British Journal of Social Work*, pp. 1-20 (advance access)

FAUBION, J. D., 2001 (reprinted 2008). Currents of Cultural Fieldwork. In: P. ATKINSON, S. DELAMONT, A. COFFEY, et al, eds, *Handbook of ethnography*. London: Sage, pp. 39-59.

FAWCETT, B., and HEARN, J., 2004. Researching others: epistemology, experience, standpoints and participation. *International Journal of Social Research Methodology*, 7(3), pp. 201-218.

FENTON, S., 2003. *Ethnicity*. Cambridge: Polity.

FETTERMAN, D. M., 1998. *Ethnography: Step by Step*. 2nd edn. Thousand Oaks, Calif.: Sage.

FISH, S., MUNRO, E. and BAIRSTOW, S., 2009. *Learning Together to Safeguard Children: Developing a Multi-agency Systems Approach for Case Reviews*. London: Social Care Institute for Excellence.

FITZGERALD, G., 2008. No Secrets, Safeguarding Adults and Adult Protection. In: J. PRITCHARD, ed, *Good Practice in Safeguarding Adults*. London: Jessica Kingsley Press, pp. 13-26.

FONTANA, A. and FREY, J. H., 2005. The Interview: From Neutral Stance to Political Involvement. In: N. K. DENZIN. and Y. K. LINCOLN, eds, *The Sage Handbook of Qualitative Research*. Third edn. Thousand Oaks: Sage, pp. 695-727.

FORSEY, M., 2008. Ethnographic Interviewing: From Conversation to Published Text. In: G. WALFORD, ed, *How to do Educational Ethnography*. London: Tufnell Press, pp. 57-76.

FOX, R. C., 2004. Observations and Reflections of a Perpetual Fieldworker. *Annals of the American Academy of Political and Social Science*, 595(1), pp. 309-326.

FULTON, K., WOODLEY, K. and SANDERSON, H., 2008. *Supported Decision Making*. Birkenhead: Paradigm.

FYSON, R. and KITSON, D., 2007. Independence or Protection - Does it have to be a Choice? Reflections on the Abuse of People with Learning Disabilities in Cornwall. *Critical Social Policy*, **27**(3), pp. 426-436.

FYSON, R. and KITSON, D., 2012. Outcomes Following Adult Safeguarding Alerts: a Critical Analysis of Key Factors. *Journal Of Adult Protection*, **14**(2), pp. 93-103.

FYSON, R., TARLETON, B. and WARD, L., 2007. Supported Living Through Supporting People: the Experiences of People with Learning Disabilities. *Housing, Care and Support*, **10**(3), pp. 35-40.

GABEL, S. and PETERS, S., 2004. Presage of a Paradigm Shift? Beyond the Social Model of Disability Toward Resistance Theories of Disability. *Disability and Society*, **19**(6), pp. 585-600.

GANGA, D. and SCOTT, S., 2006. Cultural “Insiders” and the Issue of Positionality in Qualitative Migration Research: Moving “Across” and Moving “Along” Researcher-Participant Divides. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, **7**(3), Art. 7, <http://nbn-resolving.de/urn:nbn:de:0114-fqs060379>.

GARRO, L. C., 1998. On the Rationality of Decision-Making Studies: Part 1: Decision Models of Treatment Choice. *Medical Anthropology Quarterly*, **12**(3), pp. 319-340.

GAYLARD, D., 2011. Policy to Practice In: T. SCRAGG. and A. MANTELL, eds, *Safeguarding Adults in Social Work*. Exeter: Learning Matters, pp. 9-33.

GEORGACA, E., 2013. Social Constructionist Contributions to Critiques of Psychiatric Diagnosis and Classification. *Feminism and Psychology (Special issue 'DSM-5 and Beyond: A Critical Feminist Engagement with Psychodiagnosis')*, 23(1), pp. 56-62.

GERBER, P., 2007. Globalisation, Human Capital and Learning Disabilities. *Learning Disabilities Research and Practice*, 22(3), pp. 216-217.

GIBSON, F., 2011. *Reminiscence and Life Story Work: A Practice Guide*. Fourth edn. London: Jessica Kingsley Press.

GILLHAM, B., 2000. *Case Study Research Methods*. London: Continuum.

GILLIES, V., 2011. From Theory to Practice: Methodological Reflections on Researching Inequality through Ethnography, *Researching Inequality: A Theory for Everything? Conference (Milton Keynes, The Open University)*, 6 May 2011.

GLASER, B. G. and STRAUSS, A. L., 1967. *The Discovery of Grounded Theory*. Chicago: Aldine Publishing Company.

GLASS, K. C., 1997. Refining Definitions and Devising Instruments: Two Decades of Assessing Mental Competence. *International Journal of Law and Psychiatry*, 20(1), pp. 5-33.

GODDEN, J., 2012. Integration and Disintegration of Health and Social Care Services: http://cdn.basw.co.uk/upload/basw_20153-4.pdf [accessed March 15, 2012].

GOLAFSHANI, N., 2003. Understanding Reliability and Validity in Qualitative Research. *The Qualitative Report*, **8**(4), pp. 597-607.

GOMM, R., 2011, Case Studies and Ethnography,

<http://www.methodspace.com/forum/topics/case-studies-and-ethnography?commentId=2289984%3AComment%3A62299> [accessed March 01, 2012].

GOMM, R., HAMMERSLEY, M. and FOSTER, P., 2000. *Case Study Method: Key Issues, Key texts*. London: Sage.

GOODLEY, D., 2001. 'Learning Difficulties', the Social Model of Disability and Impairment: Challenging Epistemologies. *Disability and Society*, **16**(2), pp. 207-231.

GOODLEY, D., 2003. Against a Politics of Victimisation: Disability Culture and Self-advocates with Learning Difficulties. In: S. RIDDELL. and N. WATSON, eds, *Disability, Culture and Identity*. Edinburgh. Pearson/Prentice Hall, pp. 105-130.

GOODLEY, D. and RAPLEY, M., 2002. Changing the Subject: Postmodernity and People with 'Learning Difficulties'. In: M. CORKER, and T. SHAKESPEARE, eds, *Disability/Postmodernity: Embodying Disability Theory*. London: Continuum, pp. 127-141.

GRAHAM, H., 2010. How the Tea is Made; or, the Scoping and Scaling of 'Everyday Life' in Changing Services for 'People with Learning Disabilities'. *British Journal of Learning Disabilities*, **38**(2), pp. 133-143.

GRUBB, A., 1998. Who Decides? Legislating for Incapacitated Adults. *European Journal of Health Law*, **5**(3), pp. 231-240.

GUBRIUM, J. F. and HOLSTEIN, J. A., 2008. The Constructionist Mosaic. In: J. A. HOLSTEIN. and J. F. GUBRIUM, eds, *Handbook of Social Constructionist Research*. New York: The Guildford Press, pp. 3-10.

GUDJONSSON, G., 1992. Interrogative Suggestibility: Factor Analysis of the Gudjonsson Suggestibility Scale (GSS 2). *Personality and Individual Differences*, **13**(4), pp. 479-481.

GUDJONSSON, G. H., MURPHY, G. H. and CLARE, I. C. H., 2000. Assessing the Capacity of People with Intellectual Disabilities to be Witnesses in Court. *Psychological Medicine*, **30**(2), pp. 307-314.

GUNARATNAM, Y., 2003. *Researching Race and Ethnicity: Methods, Knowledge and Power*. London: Sage Publications.

HACKING, I., 2006. Making Up People <http://www.lrb.co.uk/v28/n16/ian-hacking/making-up-people> [accessed March 19, 2013].

HACKING, I., 1999. *The Social Construction of What?* Cambridge: Harvard University Press.

HALE, B., 1997. Mentally Incapacitated Adults and Decision-making: The English Perspective. *International Journal of Law and Psychiatry*, **20**(1), pp. 59-75.

HAM, C. and OLDHAM, J., 2009. Integrating Health and Social Care in England: Lessons from Early Adopters and Implications for Policy. *Journal of Integrated Care*, 17(6), pp. 3-9.

HAMMERSLEY, M., 2009. Why Critical Realism Fails to Justify Critical Social Research. *Methodological Innovations Online*, 4(2), pp. 1-11.

HAMMERSLEY, M. and ATKINSON, P., 2007. *Ethnography: Principles in Practice*. 3 edn. Milton Park: Routledge.

HARKER, M., 2012. *Choice, Contracts, and the Mental Capacity Act 2005*. http://www.housingoptions.org.uk/general_information/gi_publications_docs/valuing_people_now_publications/Choice-Contracts-MCA.pdf: [accessed July 3, 2013]

HARRIS, S. R., 2008. Constructionism in Sociology. In: J. A. HOLSTEIN and J. F. GUBRIUM, eds, *Handbook of Social Constructionist Research*. New York: The Guildford Press, pp. 231-247.

HARRISON, G. and TURNER, R., 2011. Being a 'Culturally Competent' Social Worker: Making Sense of a Murky Concept in Practice. *British Journal of Social Work*, 41(2), pp. 333-350.

HEROD, J. and LYMBERY, M., 2002. The Social Work Role in Multi-disciplinary Teams. *Practice*, 14(4), pp. 17-27.

HEWITT, H., 2000. A Life story Approach with People with Profound Learning Disabilities. *British Journal of Nursing*, 9(2), pp. 90-95.

HIGGS, R., 2004. The Contribution of Narrative Ethics to Issues of Capacity in Psychiatry. *Health Care Analysis. (Special issue 'Mental Capacity: In Search of Alternative Perspectives')*, **12**(4), pp. 307-316.

HIRST, D. and MICHAEL, P., 2010. Family, Community and the 'Idiot' in Mid-nineteenth Century North Wales. *Disability & Society*, **18**(2), pp. 145-163.

HOLLAND, J. and THOMSON, R., 2009. Gaining Perspective on Choice and Fate. *European Societies*, **11**(3), pp. 451-469

HOLLAND, T., CLARE, I. C. H. and MUKHOPADHYAY, T., 2002. Prevalence of 'Criminal Offending' by Men and Women with Intellectual Disability and the Characteristics of 'Offenders': Implications for Research and Service Development. *Journal of Intellectual Disability Research*, **46**(1), pp. 6-20.

HOLLAND, J., 2007. Emotions and Research. *International Journal of Social Research Methodology*, **10**(3), pp. 195-209.

HOLLAND, S., BURGESS, S., GROGAN-KAYLOR, A., et al., 2011. Understanding Neighbourhoods, Communities and Environments: New Approaches for Social Work Research. *British Journal of Social Work*, **41**(4), pp. 689-707.

HOLLOMOTZ, A., 2009. Beyond 'Vulnerability': An Ecological Model Approach to Conceptualizing Risk of Sexual Violence against People with Learning Difficulties. *British Journal of Social Work*, **39**(1), pp. 99-112.

HOLLOMOTZ, A., 2012. Are We Valuing People's Choices Now? Restrictions to Mundane Choices Made by Adults with Learning Difficulties. *British Journal of Social Work*, pp. 1-18 (advance access).

HOLSTEIN, J. A. and GUBRIUM, J. F., 2004. Context: Working it Up, Down, and Across. In: C. SEALE, G. GIAMPIETRO, J. F. GUBRIUM, et al, eds, *Qualitative Research Practice*. London; Thousand Oaks, CA: Sage, pp. 267- 281

HOLTON, J. A., 2009. Qualitative Tussles in Undertaking a Grounded Theory Study. *Grounded Theory Review*, 8(3), pp. 37-49.

HOLTON, J. A., 2010. The Coding Process and Its Challenges. *Grounded Theory Review*, 9(1), pp. 21-40.

HUBERT, J., 2006. Family Carers' Views of Services for People with Learning Disabilities from Black and Minority Ethnic Groups: a Qualitative Study of 30 Families in a South London Borough. *Disability and Society*, 21(3) pp. 259-272

HUME, L. and MULCOCK, J., 2004. Awkward Places, Productive Places. In: L. HUME. and J. MULCOCK, eds, *Anthropologist in the Field: Cases in Participant Observation*. New York: Columbia University Press, pp. xi-xxvii.

HUMPHRIES, R. and CURRY, N., 2011. *Integrating Health and Social Care: Where Next?* London: Kings Fund.

HUNT, L. M. and MATTINGLY, C., 1998. Diverse Rationalities and Multiple Realities in Illness and Healing. *Medical Anthropology Quarterly (Special issue 'Rationality in the Real World: Varieties of Reasoning in Illness and Healing')*, 12(3), pp. 267-272.

HUTCHISON, J. A., JOHNSTON, H. L. and BRECKON, D. A., 2010. Using QSR-NVivo to Facilitate the Development of a Grounded Theory Project: an Account of a

Worked Example. *International Journal of Social Research Methodology*, **13**(4), pp. 283-302.

IMOH, TWUM-DANSO. A., 2011. Searching for a Middle Ground in Children's Rights in Ghana. *Journal of Human Rights*, **10**(3), pp. 376-392.

IVERSEN, R. R., 2009. 'Getting Out' in Ethnography: A Seldom-told Story. *Qualitative Social Work*, **88**(1), pp. 9-26.

JOINT COMMITTEE ON HUMAN RIGHTS, 2008. *A Life Like Any Other: The Human Rights of Adults with Learning Disabilities*. London. TSO

JENKINS, R., 2008. *Rethinking Ethnicity: Arguments and Explorations*. Second edn. London: Sage.

JENKINS, R., 1993. Incompetence and Learning Difficulties: Anthropological Perspectives. *Anthropology Today*, **9**(3), pp. 16-20.

JENKINS, R., 2000. Categorization: Identity, Social Process and Epistemology. *Current Sociology*, **48**(3), pp. 7-25.

JENKINS, R., 1998. Culture, Classification and (in)competence. In: R. JENKINS, eds, *Questions of Competence: Culture, Classification and Intellectual Disability*. Cambridge. Cambridge University Press, pp. 1-24.

JEYASINGHAM, D., 2012. White Noise: A Critical Evaluation of Social Work Education's Engagement with Whiteness Studies. *British Journal of Social Work*, **42**(4), pp. 669-686.

JOYCE, T., 2007. *Guidance on Determining the Best Interest of Adults who Lack Capacity to Make a Decision (or Decisions) for Themselves*. Leicester: British Psychological Society.

KALRA, V. S., 2006. Ethnography as Politics: A Critical Review of British Studies of Racialized Minorities. *Ethnic and Racial Studies (Special Issue 'Writing Race: Ethnography and Difference')*, **29**(3), pp. 452-470.

KAPP, B. M., 2007. Assessing Assessments of Decision-Making Capacity: A Few Legal Queries and Commentary on "Assessment of Decision-Making Capacity in Older Adults". *Journal of Gerontology: PSYCHOLOGICAL SCIENCES*, **62B**(1), pp. 12-13.

KEATING, F. and ROBERTSON, D., 2004. Fear, Black People and Mental Illness: A Vicious Circle? *Health and Social Care in the Community*, **12**(5), pp. 439-447.

KEMSHALL, H., PARTON, N., WALSH, M. et al., 1997. Concepts of Risk in Relation to Organizational Structure and Functioning within the Personal Social Services and Probation. *Social Policy and Administration*, **31**(3), pp. 213-232.

KEMSHALL, H., 2010. Risk Rationalities in Contemporary Social Work Policy and Practice. *British Journal of Social Work*, **40**(4), pp. 1247-1262.

KEMSHALL, H., 2002. *Risk, Social Policy and Welfare*. Buckingham: Open University Press.

KEOGH, B., 2005. Revisiting Classification and Identification. *Learning Disability Quarterly*, **28**(2), pp. 100-102.

KERZNER, L., 2011. Paving the Way to Full Realization of the CRPD's Rights to Legal Capacity and Supported Decision-Making: A Canadian Perspective http://www.anth.ubc.ca/fileadmin/user_upload/CIC/documents/In_From_The_Margins_Paper-Lana_Kerzner-FINAL-April_22_2011_2_.pdf [accessed April 25, 2011].

KEYWOOD, K., 2006. Healthcare Decision-making by Adults with Learning Disabilities: On-going Agendas, Future Challenges. *Psychiatry*, **5**(10), pp. 360-362.

KINSELLA, P., 2009. History of Supported Living <http://www.paradigm-uk.org/Resources/o/u/0/History%20of%20Supported%20Living.pdf> [accessed April 10, 2012].

KITZINGER, C., 2000. Social Constructionism

http://www.distance.mun.ca/media/files/wstd1000/concept/social_constructionism.php [accessed February 22, 2013].

KOZMA, A., 2008. Recent Trends in Social Services for Adults with Learning Disabilities in England. *Tizard Learning Disability Review*, **13**(4), pp. 44-47.

KOZMA, A., MANSELL, J. and BEADLE-BROWN, J., 2009. Outcomes in Different Residential Settings for People with Intellectual Disability: A Systematic Review. *American Journal on Intellectual and Developmental Disabilities*, **114**(3), pp. 193-222.

KUNDA, G., 2002. Corporate Culture. In: L. SPILLMAN, ed, *Cultural Sociology*. Massachusetts: Blackwells, pp. 88-97.

LAMBRICK, F. and GLASER, W., 2004. Sex Offenders with an Intellectual Disability. *Sexual Abuse: A Journal of Research and Treatment*, **16**(1), pp. 381-392.

LATHER, P., 2006. Paradigm Proliferation as a Good Thing to Think with: Teaching Research in Education as a Wild Profusion. *International Journal of Qualitative Studies in Education*, **19**(1), pp. 35-57.

LATHER, P., The State of Qualitative Inquiry: Methodology 2-1, *Summer Institute in Qualitative Research: Putting Theory to Work Conference (Manchester, Manchester Metropolitan University)*, 19 July 2010.

LAW COMMISSION, 1995, *Mental Incapacity*, London, HMSO.

LAW COMMISSION, 2008, *Adult Social Care: Scoping Report*. The Law Commission.

LAW COMMISSION, 2011. *Adult Social Care*. London: TSO

LAWSON, A., FRANCIS, R., RUSSELL, P. et al., 2008. Equality and Access to Human Rights for People with both Learning Disability and Mental Illness Needs. *Advances in Mental Health and Learning Disabilities*, **2**(2), pp. 3-8.

LEE, M., 2010. The Capacity to Consent to Research Among Older Adults. *Educational Gerontology*, **36**(7), pp. 592-603.

LEWIS, G., 1997. *Living the Differences: Ethnicity, Gender and Social Work*. The Open University: PhD Thesis.

LEWIS, J., BERSTOCK, P., BOVELL, V. et al., 1997. Implementing Care Management: Issues in Relating to the New Community Care. *British Journal of Social Work*, **27**(1), pp. 5-24.

LINDSAY, W. R., 2002. Research and Literature on Sex Offenders with Intellectual and Developmental Disabilities. *Journal of Intellectual Disability Research*, **46**(1), pp. 74-85.

LIPSKY, M., 1980. *Street-level Bureaucracy: Dilemmas of the Individual in Public Services*. New York: Russell Sage Foundation.

LIYANAGE, S. L., 2012. *Social Work in Community Mental Health Teams: An Ethnographic Study with Two Community Mental Health Teams*. Available at Durham E-Theses Online: <http://etheses.dur.ac.uk/3512/>; Doctoral thesis, Durham University.

LOGAN, J. R., 2012. Making a Place for Space: Spatial Thinking in Social Science. *Annual Review of Sociology*, **38**(1), pp. 507-524.

LOGIUDICE, D., SMITH, K., THOMAS, J., et al., 2006. Kimberley Indigenous Cognitive Assessment tool (KICA): Development of a Cognitive Assessment Tool for Older Indigenous Australians. *International Psychogeriatrics*, **18**(02), pp. 269.

LONDON BOROUGH OF WALTHAM FOREST CHILDREN SAFEGUARDING BOARD, 2011. Serious Case Review (Executive Summary Child W)

http://www.walthamforest.gov.uk/Documents/2011_10_21_executive_summary_child_w_v4_-_final.pdf [accessed November 12, 2012].

LONG, A. and GODFREY, M., 2004. An Evaluation Tool to Assess the Quality of Qualitative Research Studies. *International Journal of Social Research Methodology*, 7(2), pp. 181-196.

LUPTON, D., 1999. *Risk*. London: Routledge.

LUPTON, D., Sociology and risk

http://www.academia.edu/757961/1_Sociology_and_risk [accessed April 24, 2013].

MAC an GHAILL, M., 1999. *Contemporary Racisms and Ethnicities: Social and Cultural Transformations*. Buckingham: Open University Press.

MALEŠEVIC', S., 2011. Ethnicity in Time and Space: A Conceptual Analysis. *Critical Sociology*, 37(1), pp. 67-82.

MALLON, R., 2007. A Field Guide to Social Construction. *Philosophy Compass*, 2(1), pp. 93-108.

MANTHORPE, J., STEVENS, M., RAPAPORT, J., et al., 2008. Safeguarding and System Change. *British Journal of Social Work*, 39(8), pp. 1465-1480.

MASLIN-PROTHERO, S. and BENNION, A., 2010. Integrated Team Working: A Literature Review. *International Journal of Integrated Care*, 10, pp. 1-11.

MASON, D., 2000. *Race and Ethnicity in Modern Britain* 2nd edn. Oxford: Oxford University Press.

MCCALL, L., 2005. The Complexity of Intersectionality. *Signs: Journal of Women in Culture and Society*, 30(3), pp. 1771-1800.

MCCALLIN, A., 2009, Which Grounded Theory?

<http://www.groundedtheoryonline.com/what-is-grounded-theory/classic-grounded-theory> [accessed November 17, 2010].

MCCONKEY, R. and COLLINS, S., 2010. Using Personal Goal Setting to Promote the Social Inclusion of People with Intellectual Disability Living in Supported Accommodation. *Journal of Intellectual Disability Research*, **54**(2), pp. 135-143.

MCCRACKEN, G., 1986. Culture and Consumption: A Theoretical Account of the Structure and Movement of the Cultural Meaning of Consumer Goods. *Journal of Consumer Research*, **13**(1), pp. 71-84.

MCLAUGHLIN, C., 2003. The Feeling of Finding Out: the Role of Emotions in Research. *Educational Action Research*, **11**(1), pp. 67-78.

MCMANUS, R. J., WILSON, S., DELANEY, B. C., et al., 1998. Review of the usefulness of contacting other experts when conducting a literature search for systematic reviews. *BMJ*, **317**(7172), pp. 1562-1563.

MELIN, EMILSSON. U., 2013. The Role of Social Work in Cross-Professional Teamwork: Examples from an Older People's Team in England. *British Journal of Social Work*, **43**(1), pp. 116-134.

MERRIAM, S. B., 1988. *Case Study Research in Education*. San Francisco: Jossey-Bass Publishers.

- MESSERSCHMIDT, D., 1981. Anthropologists at Home in North America. In: D. MESSERSCHMIDT, ed, *Anthropologists at Home in North America*. Cambridge: Cambridge University Press, pp. 3-14
- MILLER, L., 2008. Foucauldian Constructionism. In: J. A. HOLSTEIN and J. F. GUBRIUM, eds, *Handbook of Social Constructionism*. New York: The Guildford Press, pp. 251-274.
- MILLS, S., 2010. *Michael Foucault*. London: Routledge.
- MILLS, S., 2004. *Discourse*. London: Routledge.
- MINISTRY OF JUSTICE/DEPARTMENT OF HEALTH, 2008. *Deprivation of Liberty Safeguards: Code of Practice to Supplement the Main Mental Capacity Act 2005 Code of Practice*. London: TSO.
- MIR, G. and TOVEY, P., 2002. Cultural Competency: Professional Action and South Asian Carers. *Journal of Health, Organisation and Management*, **16**(1) pp. 7-19
- MIR, G., NOCON, A., AHMAD, W., et al., 2001. *Learning Difficulties and Ethnicity*. London: Department of Health.
- MIR, G., SALWAY, S., KAI, J., et al., 2012. Principles for Research on Ethnicity and Health: the Leeds Consensus Statement. *European Journal of Public Health*, pp. 1-7 (advance access)
- MITCHELL, J. P., 2010. Introduction. In: M. MELHUUS, J. P. MITCHELL. and H. WULFF, eds, *Ethnographic Practice in the Present*. New York: Berghahn Books, pp. 1-15.

MITCHELL, W. and GLENDINNING, C. 2007. Risk and Adult Social Care: What Does UK Research Evidence Tell Us? *Risk and Rationalities Conference* <http://www.kent.ac.uk/scarr/events/Mitchell%20%20Glendinning.pdf> [accessed 27 June, 2013].

MIZOCK, L., HARKINS, D. and MORANT, R., 2011. Researcher Interjecting in Qualitative Race Research. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, **12**(2), Art. 13, <http://nbn-resolving.de/urn:nbn:de:0114-fqs1102134>.

MOORE, R., 2003. Ethnicity. In: G. BOLAFFI, R. BRACALENTI, P. BRAHAM, et al, eds, *Dictionary of Race, Ethnicity & Culture*. London: Sage Publications, pp. 94-98.

MOORE, R., 2003. Ethnic Politics. In: G. BOLAFFI, R. BRACALENTI, P. BRAHAM, et al, eds, *Dictionary of Race, Ethnicity & Culture*. London: Sage Publications, pp. 93-94.

MORIATY, J., 2011. *Qualitative Methods: Overview*. London: London School of Economics.

MORSE, J., BARRETT, M., MAYAN, M., et al., 2002. Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods*, **1**(2), pp. 13-22.

MOYE, J. and MARSON, D. C., 2007. Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research. *Journal of Gerontology: PSYCHOLOGICAL SCIENCES*, **62B**(1), pp. 3-11.

MUNRO, E., 2005. A Systems Approach to Investigating Child Abuse Deaths. *British Journal of Social Work*, **35**(4), pp. 531-546.

MUNRO, E. and HUBBARD, A., 2011. A Systems Approach to Evaluating Organisational Change in Children's Social Care. *British Journal of Social Work*, **41**(4), pp. 726-743.

MUNRO, E. R., HOLMES, L. and WARD, H., 2005. Researching Vulnerable Groups: Ethical Issues and the Effective Conduct of Research in Local Authorities. *British Journal of Social Work*, **35**(7), pp. 1023-1038.

MURJI, K. and SOLOMOS, J., 2005. Introduction: Racialization in Theory and Practice. In: K. MURJI, and J. SOLOMOS, eds, *Racialization: Studies in Theory and Practice*. Oxford: Oxford University Press, pp. 1-27.

MURPHY, E. and DINGWALL, R., 2001 (reprinted 2008). The Ethics of Ethnography. In: P. ATKINSON, A. COFFEY, S. DELAMONT, J, et al., eds, *Handbook of Ethnography*. London: Sage, pp. 339-351.

MÜTZEL, S., 2009. Networks as Culturally Constituted Processes: A Comparison of Relational Sociology and Actor-network Theory. *Current Sociology*, **57**(6), pp. 871-887.

MYRON, R. and KALATHIL, J., 2008. *Engaging with Minority Black and Ethnic Communities about the Mental Capacity Act 2005*. London: Mental Health Foundation.

NAGEL, J., 1994. Constructing Ethnicity: Creating and Recreating Ethnic Identity and Culture. *Social problems (Special issue 'Immigration, Race, and Ethnicity in America')*, **41**(1), pp. 152-176.

NANCARROW, S., ENDERBY, P., ARISS, S, et al., 2012. *The Impact of Enhancing the Effectiveness of Interdisciplinary Team Working*. National Institute for Health Research Service Delivery and Organisation Programme.

NASH, K., 2001. The 'Cultural Turn' in Social Theory: Towards a Theory of Cultural Politics. *Sociology*, **35**(1), pp. 77-92.

NHS CHOICES., 2013. Learning Disabilities: Coping with Diagnosis. <http://www.nhs.uk/Livewell/Childrenwithalearningdisability/Pages/Copingwithdiagnosis.aspx> [access June 28, 2013].

NHS CONFEDERATION, 2010. *Where Next for Health and Social Care Integration?* London: NHS Confederation.

NAYAK, A., 2005. White Lives. In: K. MURJI. and J. SOLOMOS, eds, *Racialization: Studies in Theory and Practice*. Oxford: Oxford University Press, pp. 141-162.

NAYLOR, L., 2010. Safeguarding Adults for Community Care In: K. BROWN, ed, *Vulnerable Adults and Community Care*. Exeter: Learning Matter, pp. 113-126.

NORTHFIELD, J., 2004. Factsheet – what is a learning disability? <http://www.pashunoutreach.co.uk/documents/learning-disability.pdf> [accessed June 11, 2013].

O'HARA, J., 2003. Learning Disabilities and Ethnicity: Achieving Cultural Competence. *Advances in Psychiatric Treatment*, **9**(3), pp. 166-174.

OCHIENG, B. M. N., 2010. "You Know What I Mean:" The Ethical and Methodological Dilemmas and Challenges for Black Researchers Interviewing Black Families. *Qualitative Health Research*, **20**(12), pp. 1725-1735.

O'CONNOR, D., 2010. Personhood and Dementia: Toward a Relational Framework for Assessing Decisional Capacity. *Journal of Mental Health Training, Education and Practice*, **5**(3), pp. 22-30.

O'DELL, L., DE ABREU, G. and O'TOOLE, S., 2004. The Turn to Culture. *The Psychologist*, **17**(3), pp. 138-141.

OKAI, D., OWEN, G., MCGUIRE, H., et al., 2007. Mental Capacity in Psychiatric Patients: Systematic Review. *The British Journal of Psychiatry*, **191**(4), pp. 291-297.

OLIVER, M., 1992. Changing the Social Relations of Research Production? *Disability and Society*, **7**(2), pp. 101-114.

OLIVER, M., 1996. Defining Impairment and Disability: Issues at Stake. In: C. BARNES. and G. MERCER, eds, *Exploring the Divide*. Leeds: Disability Press, pp. 29-54.

OLIVER, M., 1998. Theories of Disability in Health Practice and Research. *British Medical Journal*, **317** pp. 1446-1449.

OLUMOROTI, J. O., KASSIM, A. and HOTOPF, M., 2007. The Impact of Context on Assessments of Mental Capacity by Psychiatrists. *Journal of Mental Health*, **16**(4), pp. 521-528.

O'MALLEY, P., 2009. *Governmentality and Risk*. Legal Studies Research Paper No. 09/98 <http://ssrn.com/abstract=1478289>.: Sydney Law School.

O'REILLY, K., 2005. *Ethnographic Methods*. London: Routledge.

O'SHEA, T., 2012. Best Interest Decision-Making: Legal, Ethical and Clinical Issues <http://autonomy.essex.ac.uk/wp-content/uploads/2011/08/Report-on-Best-Interests-Public-Policy-Rountable.pdf> [accessed April 09, 2013].

O'SHEA, T., 2012. *Decision Ecologies*.

<https://morbidsymptoms.wordpress.com/2012/05/07/decision-ecologies/> [accessed June 26, 2013]

O'SHEA, T., 2011. The History of Consent <http://autonomy.essex.ac.uk/consent-in-history-theory-and-practice> [accessed June 6, 2013].

OWEN, G., OKAI, D. and HOTOPF, M., 2006. Mental Capacity. *Psychiatry*, **6**(2), pp. 69-71.

OWEN, S. G., FREYENHAGEN, F., RICHARDSON, G. et al., 2009. Mental Capacity and Decisional Autonomy: An Interdisciplinary Challenge. *Inquiry*, **52**(1), pp. 79-107.

PARK, Y., 2005. Culture as Deficit: a Critical Discourse Analysis of the Concept of Culture in Contemporary Social Work Discourse. *Journal of Sociology and Social Welfare*, **XXXII**(3), pp. 11-33.

PARTON, N., 1998. Reconfiguring Child Welfare Practices. In: A. CHAMBON, A. IRVING. and L. EPSTEIN, eds, *Reading Foucault for Social Work*. New York: Columbia University Press, pp. 103-130.

PARTON, N., 2008. From Seebohm to Think Family: Reflections on 40 years of Policy Change of Statutory Children's Social Work in England. *Child and Family Social Work*, **14**(1), pp. 68-78.

PARTON, N., 2009. Reflections on the Social Construction of Reality: A Treatise in the Sociology of Knowledge. *Social Work Now*, **44**, pp. 24-27.

PAYNE, G. and WILLIAMS, M., 2005. Generalization in Qualitative Research. *Sociology*, **39**(2), pp. 295-314.

PAYNE, M., 2005. *Modern Social Work Theory*. 3 edn. Basingstoke: Palgrave/Macmillan.

PETCH, A., 2011. *An Evidence Base for the Delivery of Adult Services*. Glasgow: Institute for Research and Innovation in Social Services.

PETERS, S., 2000. Is There a Disability Culture? A Syncretisation of Three Possible World Views. *Disability and Society*, **15**(4), pp. 583-601.

PITHOUSE, A., 1998. *Social Work: The Social Organisation of an Invisible Trade*. 2nd edn. Aldershot: Ashgate.

PITHOUSE, A., HALL, C., PECKOVER, S., et al., 2009. A Tale of Two CAFs: The Impact of the Electronic Common Assessment Framework. *British Journal of Social Work*, **39**(4), pp. 599-612.

PLUMMER, K., 2001 (reprinted 2009). The Call of Life Stories in Ethnographic Research. In: ATKINSON, P., COFFEY, A., DELAMONT, S., et al., ed, *Handbook of ethnography*. London: Sage, pp. 395-406.

PONTEROTTO, J. G., 2006. Brief Note on the Origins, Evolution, and Meaning of the Qualitative Research Concept "Thick Description". *The Qualitative Report*, **11**(3), pp. 538-549.

RABINOW, P. and ROSE, N., 2006. Biopower Today. *Biosocieties*, **1**(2), pp. 195-217.

RACE, D., 2002. Introduction - The Historical Context. In: D. RACE, ed, *Learning Disability - A Social Approach*. London: Routledge, pp. 23-52.

RAFFERTY, J. and STEYAERT, J., 2009. Editorial: Social Work in the Digital Age. *British Journal of Social Work*. (Special Issue 'Social Work in Digital Age '), **39**(4), pp. 589-598.

RAO, S., 2006. Parameters of Normality and Cultural Constructions of 'Mental Retardation': Perspectives of Bengali Families. *Disability and Society*, **21**(2), pp. 159-178.

RASALINGHAM, H., 2009. Language-Games: Race and Bewitchment. *Existential Analysis*, **20**(2), pp. 319-328.

REDLEY, M., and WEINBERG, D., 2007. Learning Disability and the Limits of Liberal Citizenship: Interactional Impediments to Political Empowerment. *Sociology of Health and Illness*, **29**(5), pp. 1-20

REDLEY, M. 2008. Citizens with Learning Disabilities and the Right to Vote. *Disability and Society*. **23**(4) pp. 375-384

Renzaho, A. M. N., McCabe, M. and Boyd, Swinburn., 2012. Intergenerational Differences in Food, Physical Activity, and Body Size Perceptions among African Migrants. *Qualitative Health Research*, **22**(6) pp. 740–754

REISSMAN, CATHERINE. K., 2001. Personal Troubles as Social Issues: A Narrative of Infertility in Context. In: I. F. SHAW. and N. G. GOULD, eds, *Qualitative Research in Social Work*. London: Sage, pp. 73-82.

RIDDELL, S. and WATSON, N., 2003. Introduction. In: S. RIDDELL and N. WATSON, eds, *Disability, culture and identity*. Harlow: Pearson/Prentice Hall, pp. 1-18.

ROETS, G., 2009. Unravelling Mr President's Nomad Lands: Travelling to Interdisciplinary Frontiers of Knowledge in Disability Studies. *Disability and Society*, **24**(6), pp. 689-701.

ROLLOCK, N., GILLBORN, D., VINCENT, C. et al., 2011. The Public Identities of the Black Middle Classes: Managing Race in Public Spaces. *Sociology*, **45**(6), pp. 1078-1093.

ROSE, N., 1996. The Death of the Social? Re-figuring the Territory of Government. *Economy and Society*, **25**(3), pp. 327-356.

ROSE, N., 1999. *Governing the Soul: the Shaping of the Private Self*. 2 edn. London: Free Association Books.

ROSE, N., O'MALLEY, P. and VALVERDE, M., 2006. Governmentality. *Annual Review of Law and Social Science*, **2**, pp. 83-104.

ROTH, L. H., MEISEL, A. and LIDZ, C. W., 1977. Tests of Competency to Consent to Treatment. *The American Journal of Psychiatry*, **134**(3), pp. 279-284.

ROYAL COLLEGE OF PSYCHIATRISTS, 2008. *Rethinking Risk to Others in Mental Health Services*. London.

RYAN, F., 2012. Forced Marriage Blights the Lives of Scores of Learning Disabled People. *The Guardian*.

SAARIO, S. and STEPNEY, P., 2009. Managerial Audit and Community Mental Health: a Study of Rationalising Practice in Finnish Psychiatric Out-patient Clinics. *European Journal of Social Work*, **12**(1), pp. 41-56.

SAKS, E. R. and JESTE, D. V., 2006. Capacity to Consent to or Refuse Treatment and/or Research: Theoretical Considerations. *Behavioral Sciences and the Law*, **24**(4), pp. 411-429.

SALWAY, S., ALLMARK, P., BARLEY, R., et al., 2009. Researching Ethnic Inequalities. *Social Research Update*, **58**, pp. 1-4

SANGER, J., 1996. *The Compleat Observer?: a Field Research Guide to Observation*. London: Falmer Press.

- SCANLON, D., 2005. The Future of Learning Disability *Learning Disabilities Quarterly (Special Issue 'The Future of Learning Disabilities')*, **28**(2), pp. 91
- SCHENSUL, S., SCHENSUL, J. J. and LECOMPTE. M. D. 1999. *Essential Ethnographic Methods*. Walnut Creek. Altamira Press
- SCOTT-JONES, J. and WATT, S., 2010. Doing Participant Observation. In: J. SCOTT-JONES and S. WATT, eds, *Ethnography in Social Science Practice*. London: Routledge, pp. 107-125.
- SEALE, C., 1999. Quality in Qualitative Research. *Qualitative Inquiry*, **15**(4), pp. 465-478.
- SEARLE, J. R., 1996. *The construction of social reality*. London: Penguin.
- SERRANT-GREEN, L., 2002. Black on black: methodological issues for black researchers working in minority ethnic communities. *Nurse Researcher*, **9**(4), pp. 30-44.
- SHAH, A., BANNER, N., NEWBIGGING, K., et al., 2009. The Early Experience of Consultant Psychiatrists in Application of the Mental Capacity Act: Issues for Black and Minority Individuals. *Ethnicity in Inequalities in Health and Social Care*, **2**(2), pp. 4-10.
- SHAH, A. and HEGINBOTHAM, C., 2008. The Mental Capacity Act: Some Implications for Black and Minority Ethnic Elders. *Age and Ageing*, **37**(3), pp. 242-243.

SHAW, I., 2007. Is Social Work Research Distinctive? *Social Work Education*, **26**(7), pp. 659-669.

SHAW, I., BELL, M., SINCLAIR, I., et al., 2009. An Exemplary Scheme? An Evaluation of the Integrated Children's System. *British Journal of Social Work*, **39**(4), pp. 613-626.

SHAW, I., 2012. The Positive Contributions of Quantitative Methodology to Social Work Research. *Research on Social Work Practice*, **22**(2), pp. 129-134.

SHAW, I. F. and GOULD, N. G., 2001. Fieldwork Choices in Context. In: I. F. SHAW and N. G. GOULD, eds, *Qualitative research in Social Work*. London: Sage, pp. 135-156.

SHIER, M. L. and GRAHAM, J. R., 2011. Work-related Factors that Impact Social Work Practitioners' Subjective Well-being: Well-being in the Workplace. *Journal of Social Work*, **11**(4), pp. 402-421.

SILVERMAN, D., 2000. Analyzing Talk and Text. In: N. K. DENZIN and Y. S. LINCOLN, eds, *Handbook of qualitative research*. 2 edn. Thousand Oaks, Calif.: Sage Publications, pp. 821-834.

SIMINSKI, P., 2003. Patterns of Disability and Norms of Participation Through the Life Course: Empirical Support for a Social Model of Disability. *Disability and Society*, **18**(6), pp. 707-718.

SIMMONS, K. and WATSON, D., 1999. *The View From Arthurs Seat: A Literature Review of Housing and Support Options 'Beyond Scotland'*. Edinburgh: The Scottish Office Central Research Unit.

SIMPSON, M. K. and HOGG, J., 2001. Patterns of Offending Among People with Intellectual Disability: A Systematic Review. Part 1. Methodology and Prevalence Data. *Journal of Intellectual Disability Research*, **45**(5), pp. 384-396.

SMITH, S. J., 2010. *Living With Risk: Exploring the Concept of Risk with Adults with Learning Difficulties*. PhD Thesis. Glasgow University.

SOCIAL CARE INSTITUTE FOR EXCELLENCE WITH THE PAN LONDON ADULT SAFEGUARDING EDITORIAL BOARD, 2011. *Protecting Adults at Risk: London Multi-agency Policy and Procedures to Safeguard Adults from Abuse*. Great Britain: Social Care Institute for Excellence.

SOYSAL, L., 2009. Introduction: Triumph of Culture, Troubles of Anthropology. *Focaal: The European Journal of Anthropology*, **2009**(55), pp. 3-11.

SPARKES, A. C., 2009. Novel Ethnographic Representations and the Dilemmas of Judgement. *Ethnography and Education*, **4**(3), pp. 301-319.

STAKE, R. E., 1995. *The Art of Case Study Research*. Thousand Oaks: Sage Publications.

STALKER, K., 1998. Some Ethical and Methodological Issues in Research with People with Learning Difficulties. *Disability and Society*, **13**(1), pp. 5-19.

STANFIELD, J. H., 2011. Epistemological Reconsiderations and New Considerations. In: J. H. STANFIELD H., ed, *Rethinking Race and Ethnicity in Research Methods*. Walnut Creek: Left Coast Press, pp. 11-26.

STANFORD, S., 2010. 'Speaking Back' to Fear: Responding to the Moral Dilemmas of Risk in Social Work Practice. *British Journal of Social Work (Special Issue 'Risk and Social Work: Critical Perspectives')*, **40**(4), pp. 1065-1080.

STANLEY, N. and MANTHORPE, J., 2008. Small Acts of Care: Exploring the Potential Impact of the Mental Capacity Act 2005 on Day-to-Day Support. *Social Policy and Society*, **8**(1), pp. 37-48.

STEVENS, A., 2004. Closer to Home: A Critique of British Government Policy Towards Accommodating Learning Disabled People in Their Own Homes. *Critical Social Policy*, **24**(2), pp. 233-254.

STEVENS, A. R. A., 2008. Social Models of Disability and Social Work in the Twenty-first Century. *Ethics and Social Welfare*, **2**(2), pp. 197-202.

STURMAN, E. D., 2005. The Capacity to Consent to Treatment and Research: A Review of Standardized Assessment Tools. *Clinical Psychology Review*, **25**(7), pp. 954-974.

SYSON, G. and BOND, J., 2010. Integrating Health and Social Care Teams in Salford. *Journal of Integrated Care*, **18**(2), pp. 17-24.

TAN, J. O. A., HOPE, T., STEWART, A., et al., 2006. Competence to Make Treatment Decisions in Anorexia Nervosa: Thinking Processes and Values. *Philosophy, Psychology and Psychiatry*, **13**(4), pp. 267-282.

TAVORY, I. and TIMMERMAN, S., 2009. Two Cases of Ethnography: Grounded Theory and the Extended Case Method. *Ethnography*, **10**(3), pp. 243-263.

TAYLOR, B. J., 2005. Risk Management Paradigms in Health and Social Services for Professional Decision Making on the Long-Term Care of Older People. *British Journal of Social Work*, **36**(8), pp. 1411-1142.

TAYLOR, I., 2004. Multi-professional Teams and Learning Organisations In: N. GOULD. and M. BALDWIN, eds, *Social work, Critical Reflection and the Learning Organisation*. Aldershot: Ashgate, pp. 75-86.

TAYLOR, S. J., 2000. "YOU'RE NOT A RETARD, YOU'RE JUST WISE": Disability, Social Identity, and Family Networks. *Journal of Contemporary Ethnography*, **29**(1), pp. 58-92.

TAYLOR-GOOBY, P. and ZINN, J. O., 2006. Current Directions in Risk Research: New Developments in Psychology and Sociology. *Risk Analysis: An International Journal*, **26**(2), pp. 397-411.

TEDLOCK, B., 2000. Ethnography and Ethnographic Representation. In: N. K. DENZIN and Y. S. LINCOLN, eds, *Handbook of qualitative research*. 2 edn. Thousand Oaks: Sage Publications, pp. 455-486.

TEW, J., 2006. Understanding Power and Powerlessness: Towards a Framework for Emancipatory Practice in Social Work. *Journal of Social Work*, **6**(1), pp. 33-51.

THOMASSEN, B., 2009. The Uses and Meanings of Liminality. *International Political Anthropology*, **2**(1), pp. 5-28.

THOMSON, R., HOLLAND, J., MCGRELLIS, S., et al., 2005. Inventing Adulthood: A Biographical Approach to Understanding Youth Citizenship. *Sociological Review*, **52**(2), pp. 218-239.

THOMSON, R., BELL, R., HOLLAND, J., et al., 2002. Critical Moments: Choice, Chance and Opportunity in Young People's Narratives of Transition. *Sociology*, **36**(2), pp. 335-354.

TITTERTON, M., 2005. *Risk and Risk Taking in Health and Social Care*. London: Jessica Kingsley Press.

TOWNEND, M. and BRAITHWAITE, T., 2002. Mental Health Research – the Value of User Involvement. *Journal of Mental Health*, **11**(2), pp. 117-119.

TRAUSTADÓTTIR, R. and SIGURJÓNSDÓTTIR, H. B., 2008. The 'Mother' behind the Mother: Three Generations of Mothers with Intellectual Disabilities and their Family Support Networks. *Journal of Applied Research in Intellectual Disabilities*, **21**(4), pp. 331-340

TREMAIN, S., 2005. Foucault, Governmentality, and Critical Disability Theory. In: S. TREMAIN, ed, *Foucault and the Government of Disability*. Ann Arbor: University of Michigan Press, pp. 1-24.

TREVILLION, S., 2007. Health, Disability and Social Work: New Directions in Social Work Research. *British Journal of Social Work*, **37**(5), pp. 937-946.

TSOLIDIS, G., 2008. The (im)possibility of Poststructuralist Ethnography - Researching Identities in Borrowed Space. *Ethnography and Education*, **3**(3), pp. 271-281.

TURNER, M. and BERESFORD, P., 2005. *User Controlled Research: Its Meanings and Potential*. Brunel University: Shaping Our Lives and Centre for Citizenship Participation.

TURNER, V. W., 1966. *The Forest of Symbols*. Ithaca: Cornell University Press.

TURNER, V. W., 1969. *The Ritual Process: Structure and Anti-structure*. London: Routledge and Paul Kagan.

TURNING POINT, 2010. *Benefits Realisation: Assessing the Evidence for the Cost Benefit and Cost Effectiveness of Integrated Health and Social Care*. London: Turning Point.

UNISON. 2007. *Report on the Integration of Health and Social Care Services in England*. London.

VAN GENNEP, A., 1960. *The Rites of Passage*. Chicago, IL: University of Chicago Press.

VAN MAANEN, J., 1990. GREAT MOMENTS IN ETHNOGRAPHY: An Editor's Introduction. *Journal of Contemporary Ethnography*, **19**(1), pp. 3-7.

VAN MAANEN, J., 1995. An End to Innocence: The Ethnography of Ethnography. In: J. VAN MAANEN, ed, *Representation in Ethnography*, Thousand Oaks: Sage, pp. 1-35.

VERSCHUREN, P. J. M., 2003. Case Study as a Research Strategy: Some Ambiguities and Opportunities. *International Journal of Social Research Methodology*, **6**(2), pp. 121.

WALFORD, G., 2009. The Practice of Writing Ethnographic Field Notes. *Ethnography and Education*, **4**(2), pp. 117-130.

WALLCRAFT, J. and SWEENEY, A., 2011. *User Involvement in Adult Safeguarding*. Great Britain: Social Care Institute for Excellence.

WALMSLEY, J. and JOHNSON, K., 2003. *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. London: Jessica Kingsley Publishers.

WARNER, J. and SHARLAND, E., 2010. Editorial. *British Journal of Social Work (Special Issue 'Risk and Social Work: Critical Perspectives')*, **40**(4), pp. 1035-1045.

WARREN, C. A. B., 2001 (Reprinted 2009). Qualitative Interviewing. In: J. F. GUBRIUM. and J. A. HOLSTEIN, eds, *Handbook of Interview Research*. Thousand Oaks: Sage Publications, pp. 83-102.

WEBB, S. A., 2006. *Social Work in a Risk Society: Social and Political Perspectives*. Basingstoke: Palgrave Macmillan.

WEINBERG, D., 2008. The Philosophical Foundations of Constructionist Research. In: J. A. HOLSTEIN and J. F. GUBRIUM, eds, *Handbook of Constructionist Research*. New York: The Guildford Press, pp. 13-39.

WHITE, C., OAKES, P. and MARSLAND, D., 2007. Abuse in Care? The Identification of the Early Indicators of People with Learning Disabilities in Residential Setting. *Journal Of Adult Protection*, **9**(4), pp. 6-22.

WHITE, S., HALL, C. and PECKOVER, S., 2008. The Descriptive Tyranny of the Common Assessment Framework: Technologies of Categorization and Professional Practice in Child Welfare. *British Journal of Social Work*, **39**(7), pp. 1197-1217.

WHYTE, S. R., 1998. Slow Cookers and Madmen: Competence of Heart and Head in Rural Uganda. In: R. JENKINS, ed, *Questions of Competence: Culture, Classification and Intellectual Disability*. Cambridge: Cambridge University Press, pp. 153-175.

WILKINS, D. and BOAHEN, G., 2013. *Critical Analysis for Social Workers*. Maidenhead: Open University Press.

WILSON, P., 1996. The Law Commission's report on Mental Incapacity: Medically Vulnerable Adults or Politically Vulnerable Law. *Medical Law Review*, 4(3), pp. 227-249.

WINNICK, B. J., 1995. The Side Effects of Incompetency Labelling and the implications for Mental Health Law. *Psychology, Public Policy, and Law*, 1(1), pp. 6-42.

WISTOW, G., 2012. Still a Fine Mess? Local Government and the NHS 1962 to 2012. *Journal of Integrated Care*, 20(2), pp. 101-114.

WOLFINGER, N. H., 2002. On Writing Field Notes: Collection Strategies and Background Expectancies. *Qualitative Research*, 2(1), pp. 85-95.

WONG, J. G., CLARE, I. C. H., HOLLAND, A. J., et al., 2000. The Capacity of People with a 'Mental Disability' to Make a Health Care Decision. *Psychological Medicine*, 30, pp. 295-306.

WONG, J. G., CLARE, I. C. H., GUNN, M. J., et al., 1999. Capacity to Make Health Care Decisions: It's Importance in Clinical Practice. *Psychological Medicine*, 29(2), pp. 437-446.

WRIGHT, D., 2000. Learning Disability and the New Poor Law in England, 1834–1867. *Disability and Society*, **15**(1), pp. 731-745.

WUTHNOW, R., DAVISON, H. D., BERGESEN, A. J., et al., 1984. *Cultural analysis: the work of Peter L Berger Mary Douglas Michel Foucault and Jurgen Habermas*. Abingdon: Routledge

YAR, M., 2003. Panoptic Power and the Pathologisation of Vision: Critical Reflections on the Foucauldian Thesis. *Surveillance & Society*, **1**(3), pp. 254-271.

YATES, S., 2005. Truth, Power, and Ethics in Care Services for People with Learning Difficulties. In: S. TREMAIN, ed, *Foucault and the Government of Disability*. Ann Arbor: University of Michigan Press, pp. 78-92.

YIN, R. K., 2009. *Case Study Research: Design and Methods*. 4th edn. Los Angeles, Calif.: Sage Publications.

ZERUBAVEL, E., 1996. Lumping and Splitting: Notes on Social Classification. *Sociological Forum (Special Issue: 'Lumping and Splitting')*, **11**(3), pp. 421-433.

ZINN, J. O., 2006. Risk, Affect and Emotion. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, **7**(1), Art. 29, <http://nbn-resolving.de/urn:nbn:de:0114-fqs0601293>.

ZUBAIR, M., 'Ethnic matching' in Minority Ageing Research: Some Reflections on the Opportunities, Challenges and the Limits, *Developing research capacity in black and ethnic minority ageing studies Conference (London, Brunel University)*, 8 November 2012.

